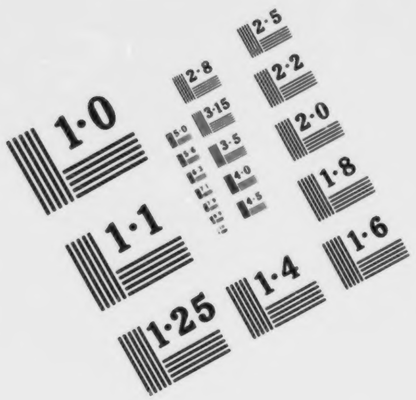
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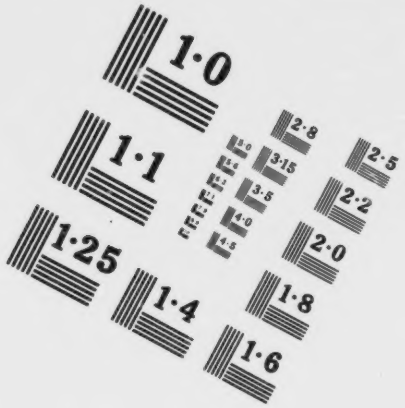
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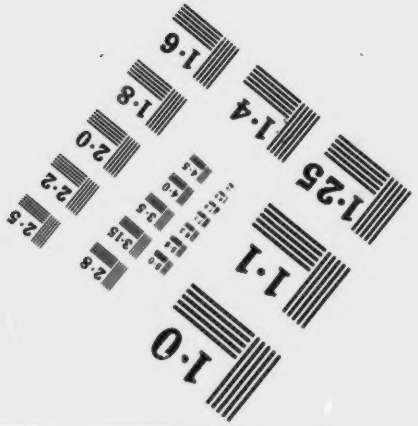
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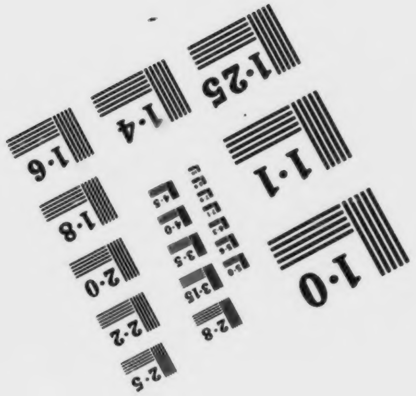
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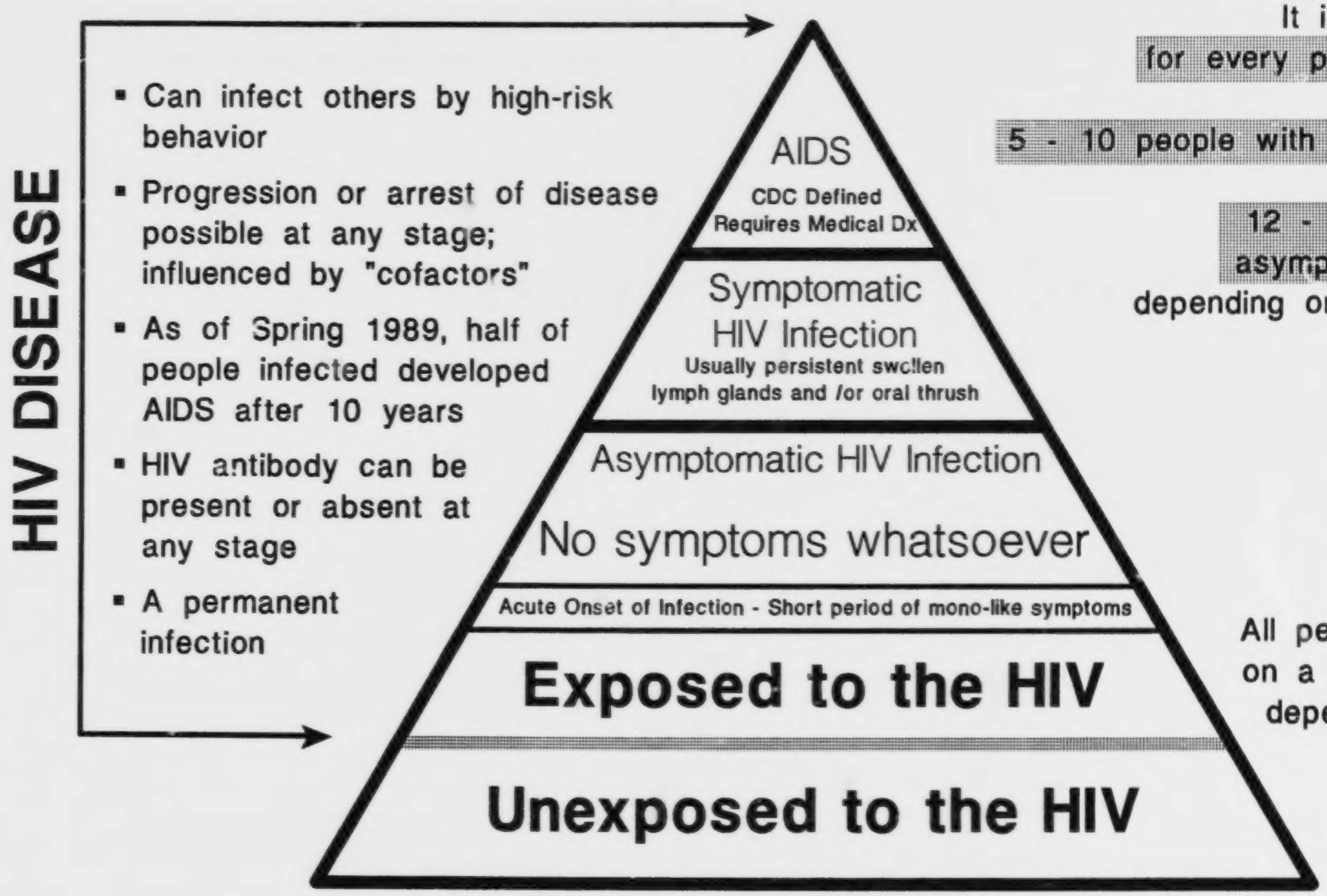
The HIV Pyramid

November 1989



HIV DISEASE

- Can infect others by high-risk behavior
- Progression or arrest of disease possible at any stage; influenced by "cofactors"
- As of Spring 1989, half of people infected developed AIDS after 10 years
- HIV antibody can be present or absent at any stage
- A permanent infection

AIDS
CDC Defined
Requires Medical Dx

Symptomatic HIV Infection
Usually persistent swollen lymph glands and /or oral thrush

Asymptomatic HIV Infection
No symptoms whatsoever

Acute Onset of Infection - Short period of mono-like symptoms

Exposed to the HIV

Unexposed to the HIV

It is estimated that for every person with AIDS there are 5 - 10 people with some symptoms and 12 - 100 people with asymptomatic infection depending on the population.

All people are at risk on a continuing basis depending on their behavior.

VA 1.2:

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AIDS
PROGRAM OFFICE
DEPARTMENT OF
VETERANS AFFAIRS

AIDS Program Office

Director	Susan H. Mather, M.D., M.P.H.
Deputy Director	Robert E. Allen, PH.D.
Nurse Epidemiologist	Bobbie R. Peterson, PH.D., M.P.H.
Program Assistant	Barbara Brandau
Secretary / Steno	Norma J. Donley

Address: 10B/AIDS
VA Central Office
810 Vermont Av., N.W.
Washington, D.C. 20420

Phone:	FTS 373-2621	Local 233-2621
	-3631	-3631
	-3072	-3072

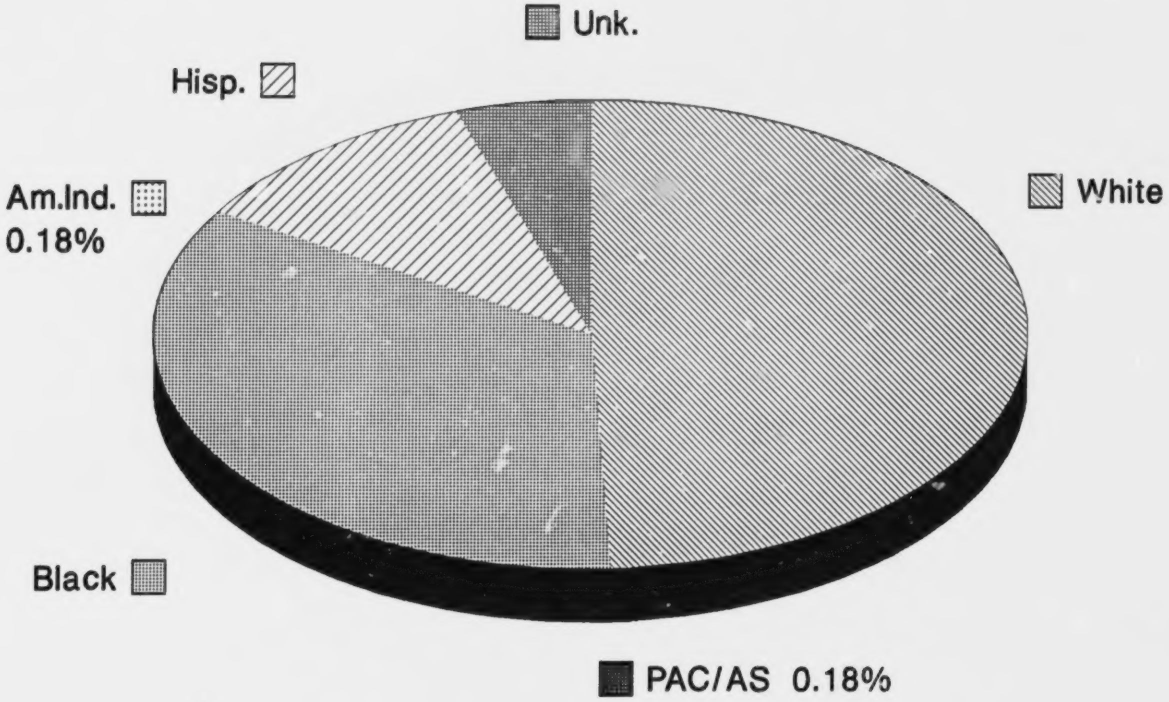
AIDS Cases Projected by Year
1988 Through 1992

Year	USA Estimate	VA(6%)	68% Prediction Interval
1988	39,000	2,340	32,000 - 41,000
1989	49,000	2,940	32,000 - 56,000
1990	60,000	3,600	28,000 - 73,000
1991	71,000	4,260	21,000 - 94,000
1992	80,000	4,800	13,000 - 119,000
Total through 1992			
	365,000	21,900	205,000 - 440,000

Public Health Reports, Vol.103, Supp. 1, 1988

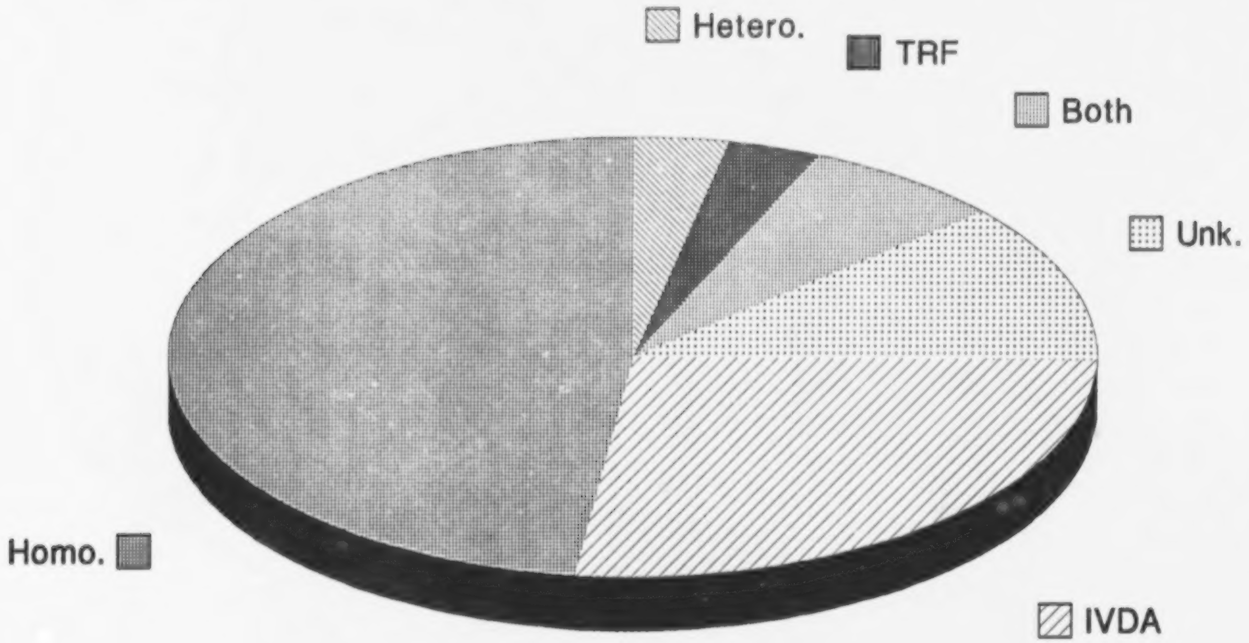
VA Aids Registry

Race and Ethnic Groups



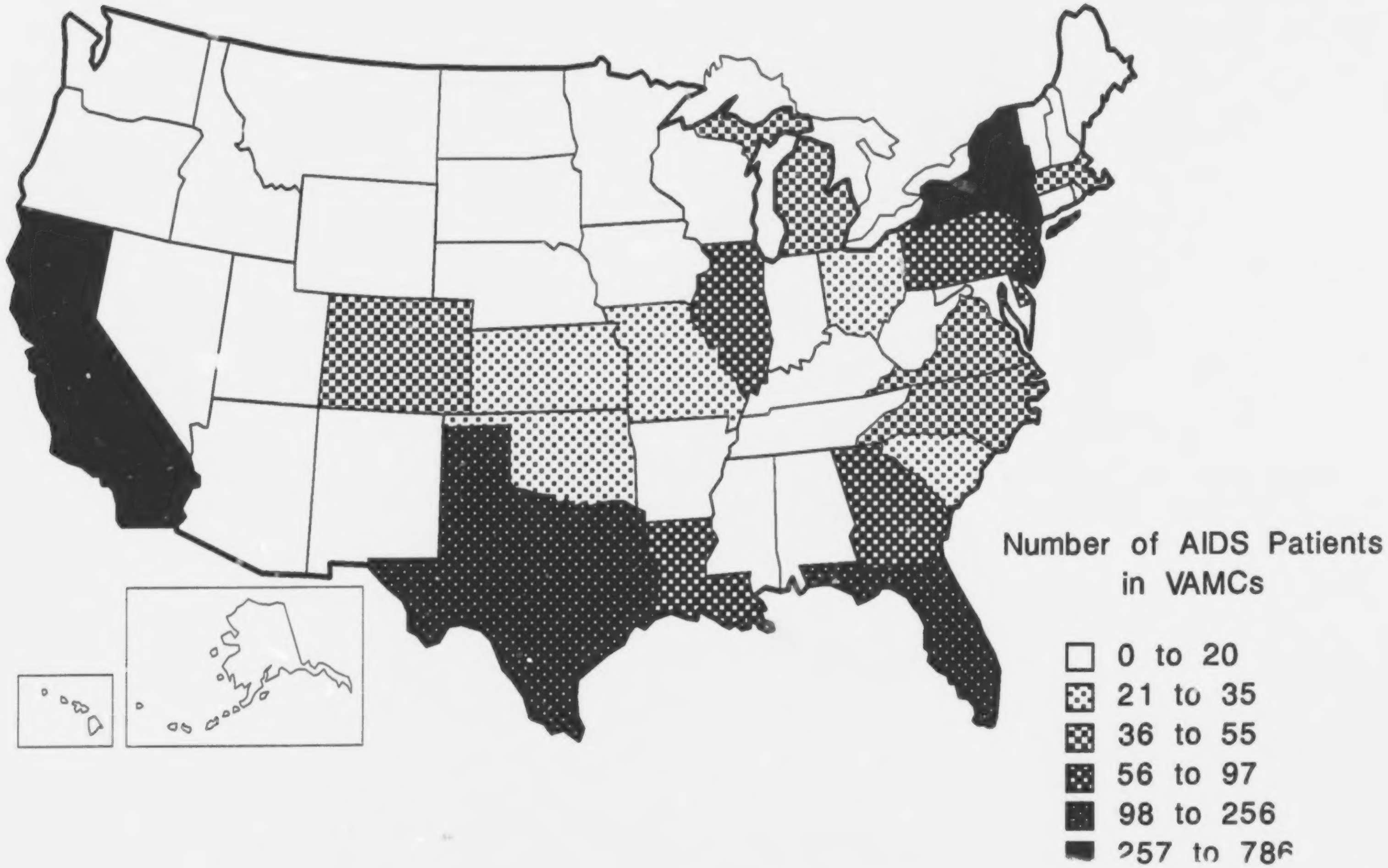
VA Aids Registry

Risk Factor



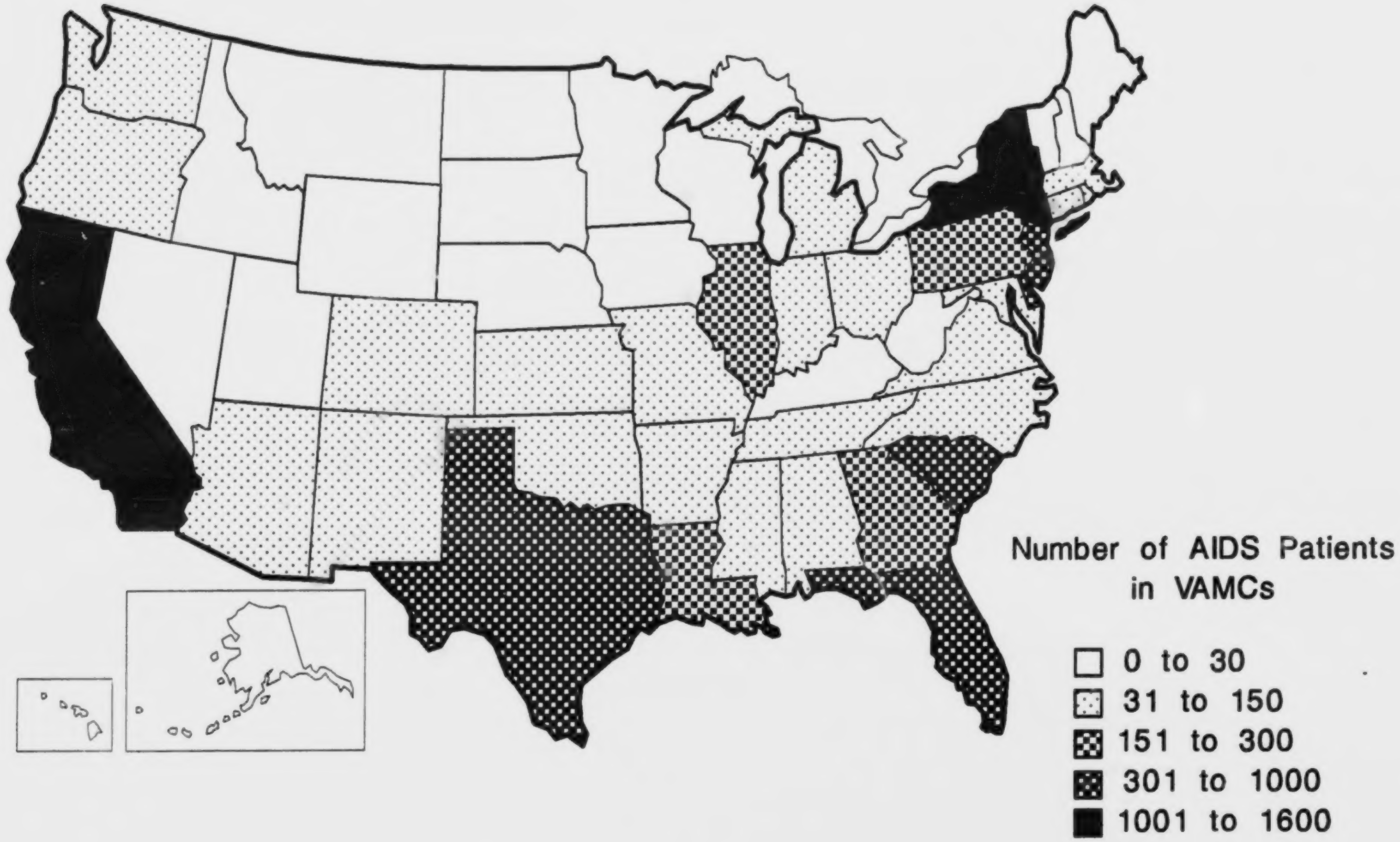
Epicenters of AIDS in VA Cases by State

(cumulative as of November 1987)


Number of AIDS Patients in VAMCs
☐ 0 to 20
▨ 21 to 35
▨ 36 to 55
▨ 56 to 97
■ 98 to 256
■ 257 to 786

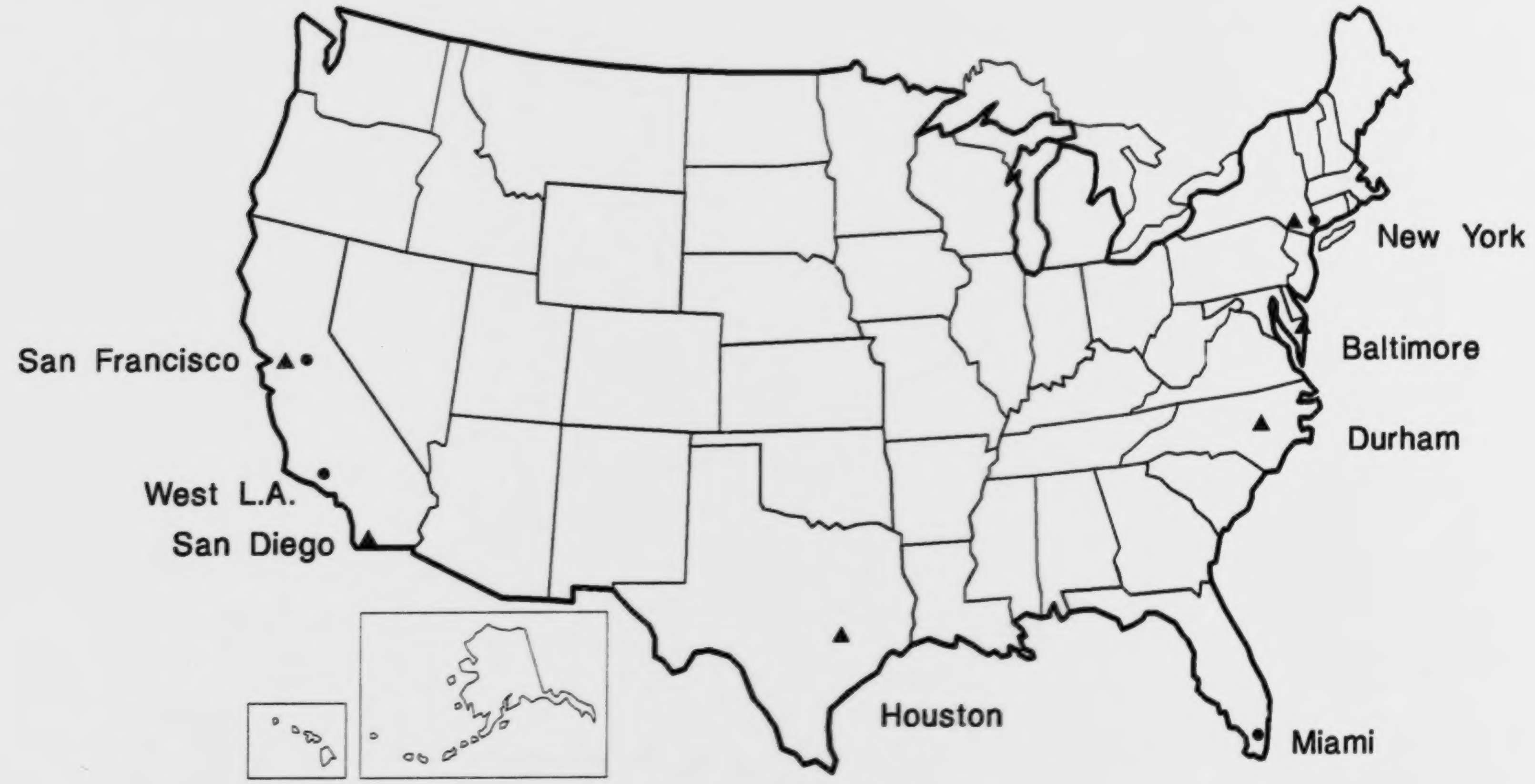
VA AIDS Patient Registry

As of December 31, 1989


Number of AIDS Patients in VAMCs
☐ 0 to 30
░ 31 to 150
▒ 151 to 300
▓ 301 to 1000
■ 1001 to 1600

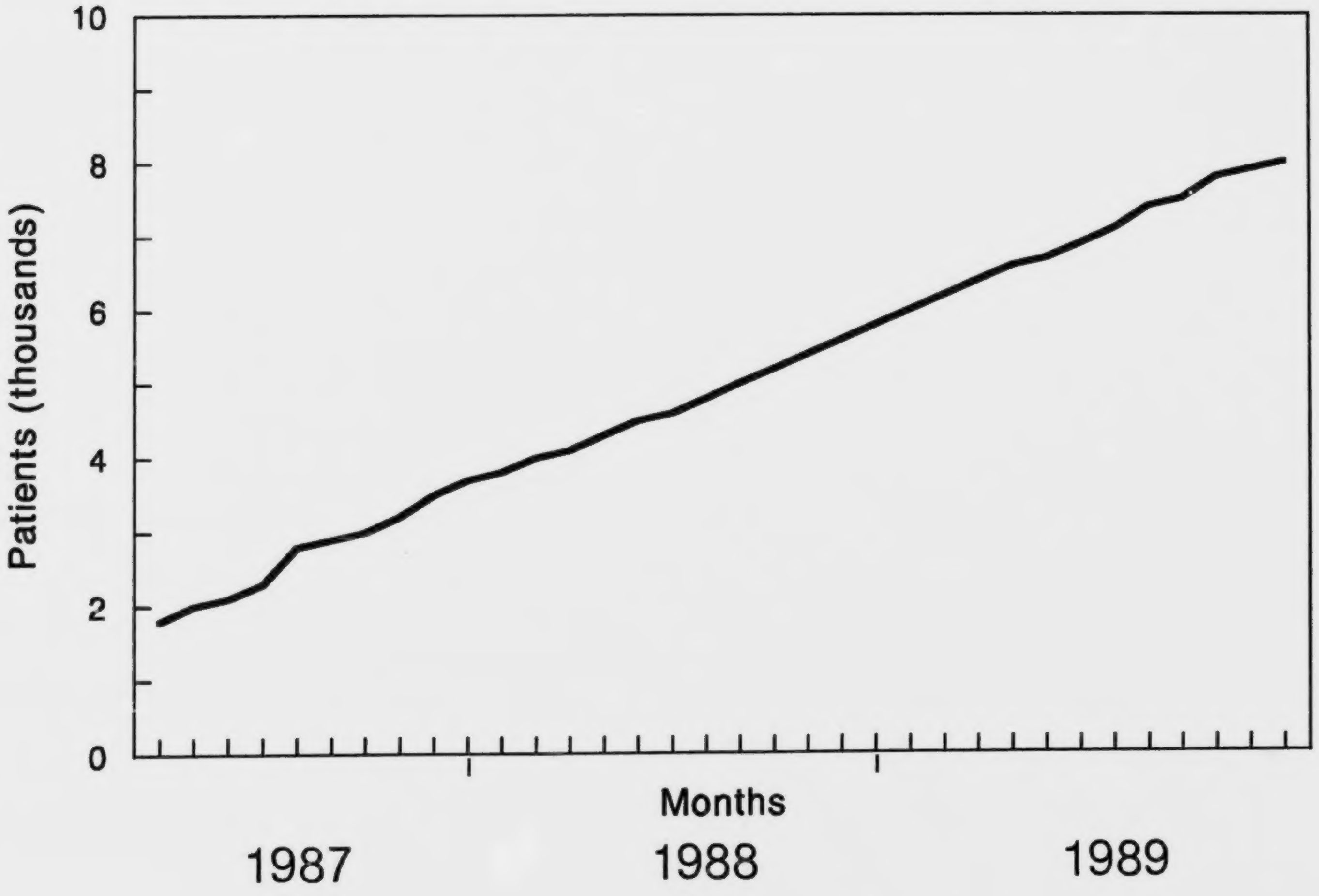
Department of Veterans Affairs

Special Emphasis Programs in AIDS

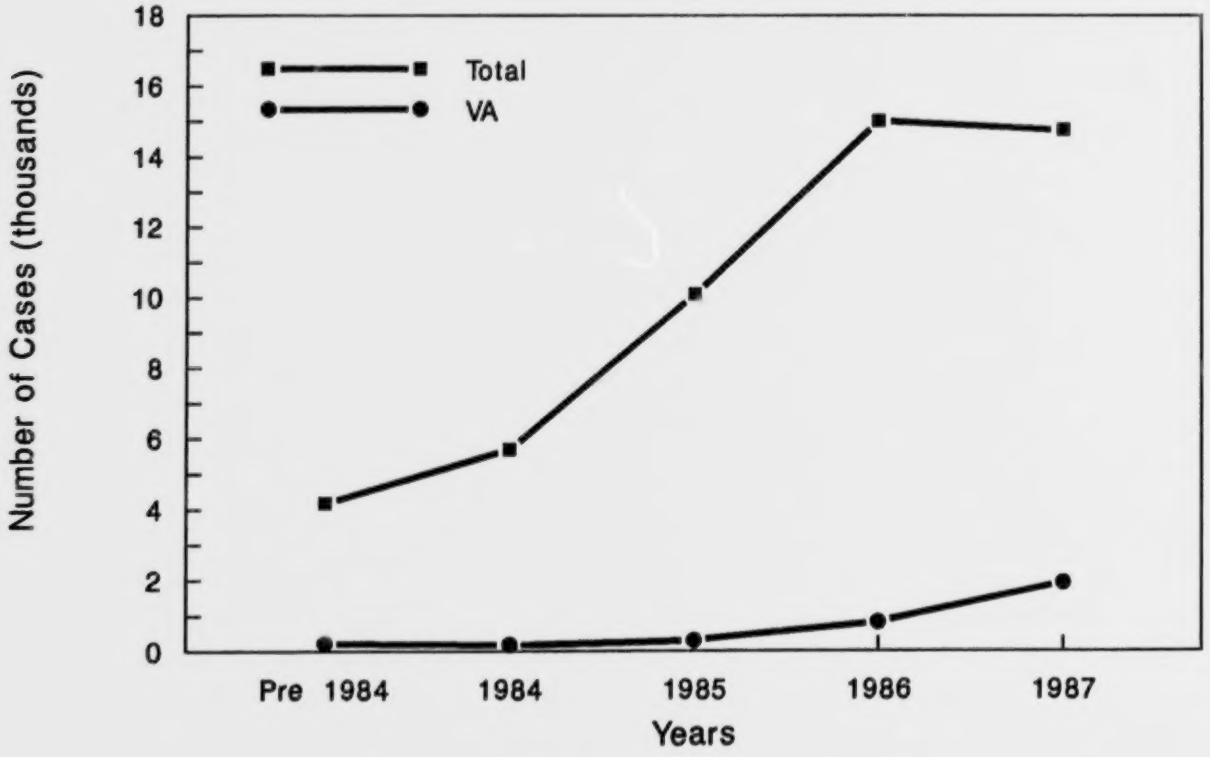

San Francisco
West L.A.
San Diego
Houston
Miami
Durham
Baltimore
New York

- • Clinical AIDS Units
- ▲ AIDS Research Centers

Total Aids Cases in VA
VA Aids Registry



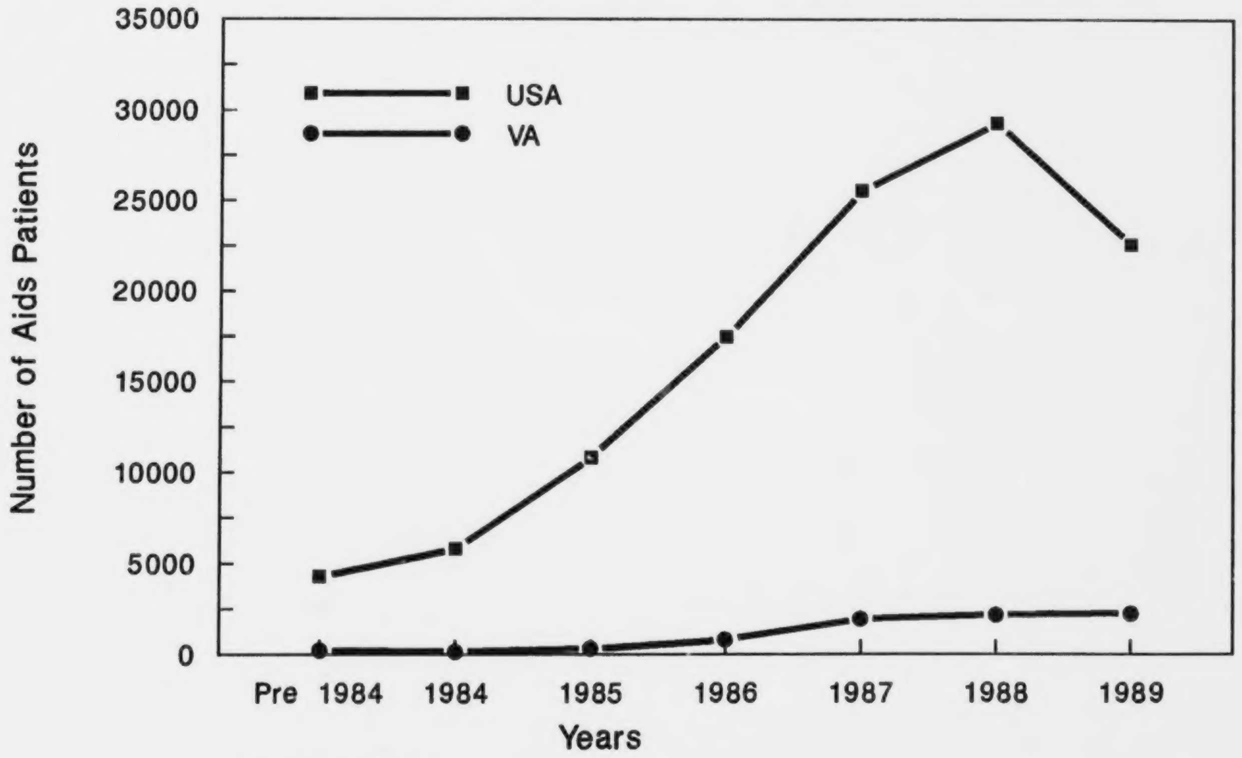
Number of Cases Reported in USA



VA Percent	5.05	3.32	3.14	5.52	13.06

142.000771.90

Comparison of VA Aids Cases to Adult Aids Cases by Year



VA Percent:

Pre 1984	1984	1985	1986	1987	1988	1989
4.9	3.2	2.9	4.7	7.5	7.4	9.9

Comparison of Ethnic Groups
VA vs. USA Population

Ethnic Groups	VA(%)	USA (%)
White	46	61
Black	32	25
Hispanic	11	14
Unknown / Unreported	10	1

December 31, 1987

Comparison of Risk Factors
VA vs. USA Population

Risk Factor	VA(%)	USA (%)
Homosexual / Bisexual	46	65
IV Drug Abuser	25	17
Both	7	8
Hemophiliac	-	1
Heterosexual Contacts	2	4
Transfusion	3	2
Unknown / Unreported	15	3

December 31, 1987

Number of Aids Patients Reported Since 1979

VAMC	Number of Patients	Percent of Total
New York	411	11.83
West Los Angeles	224	6.45
Bronx	188	5.41
San Francisco	183	5.27
Brooklyn	169	4.87
Miami	160	4.61
Houston	152	4.38
East Orange	139	4.00

December 31, 1987

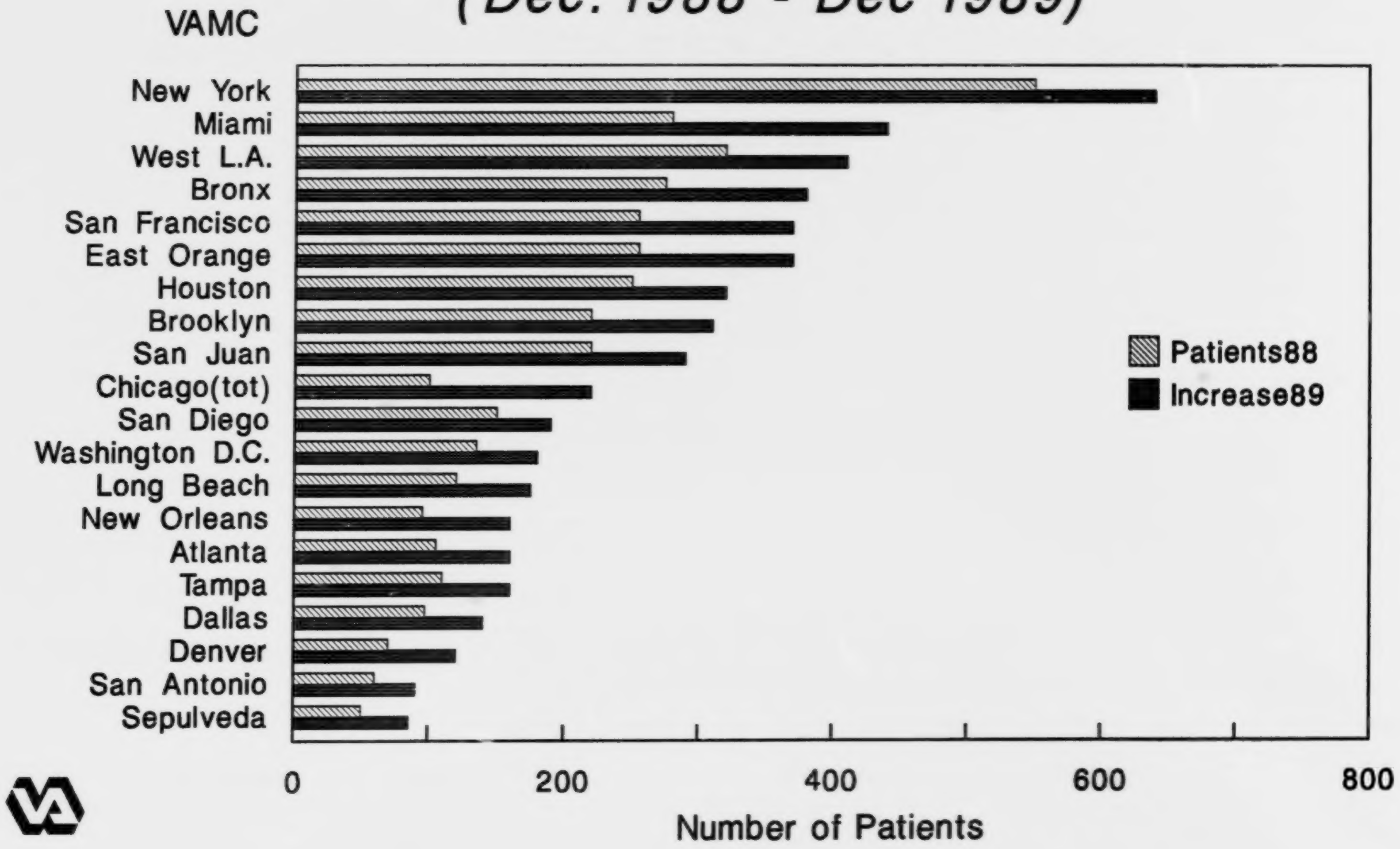
Total in 1987 = 3473

142.000771.90

VA Aids Registry

Year to date

(Dec. 1988 - Dec 1989)



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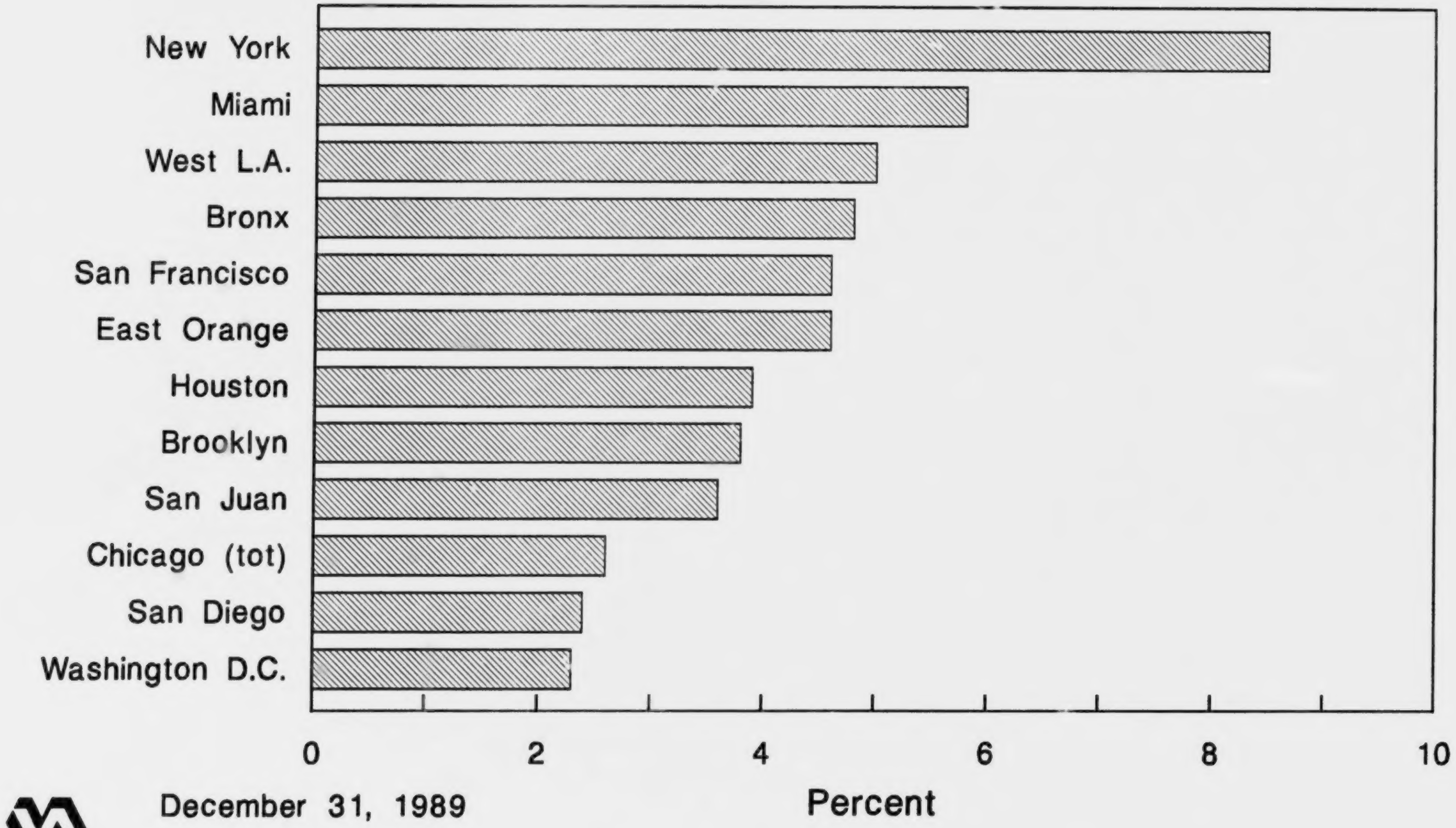
Aids Patient Registry

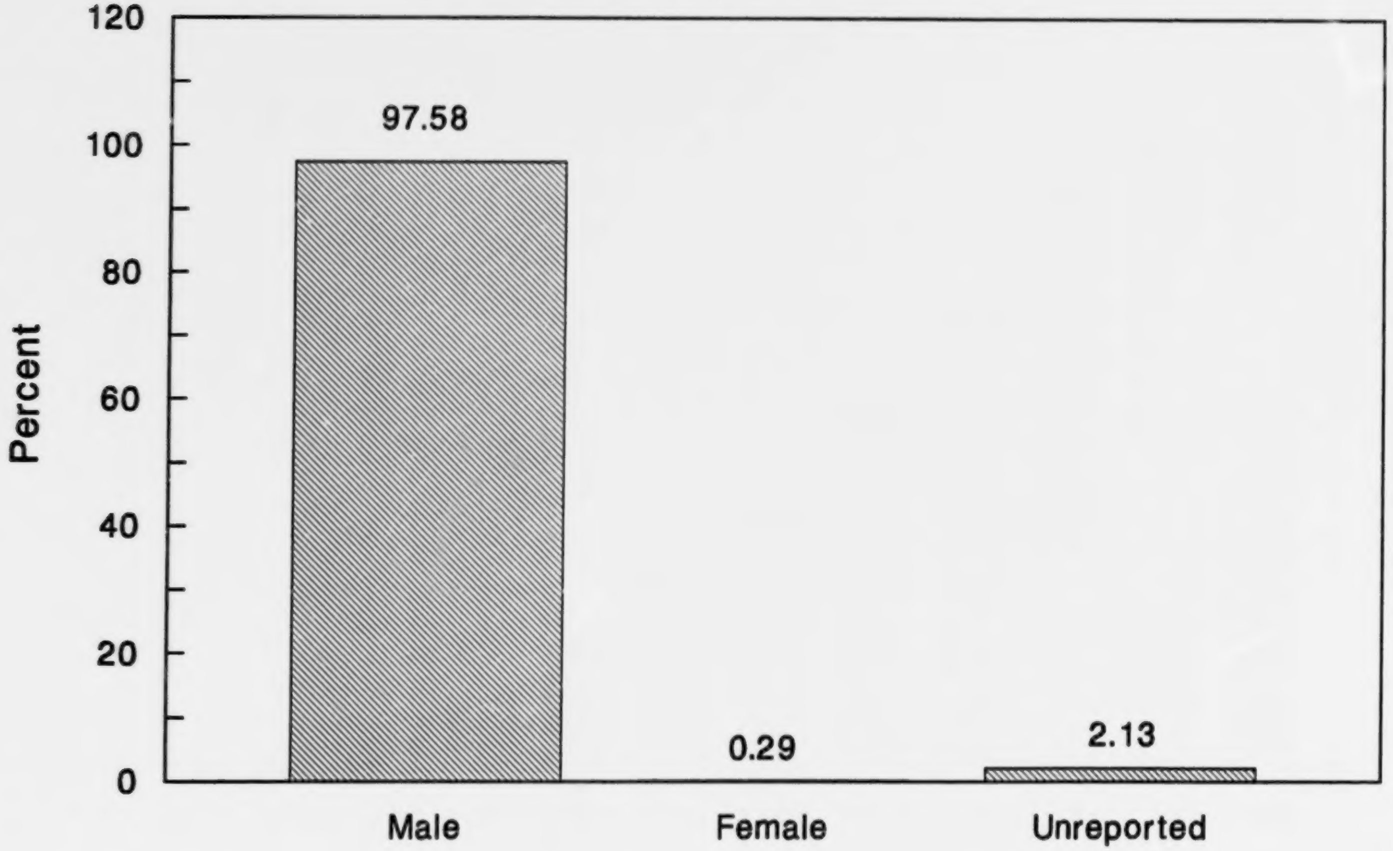
(cum. 52.32%)



December 31, 1989

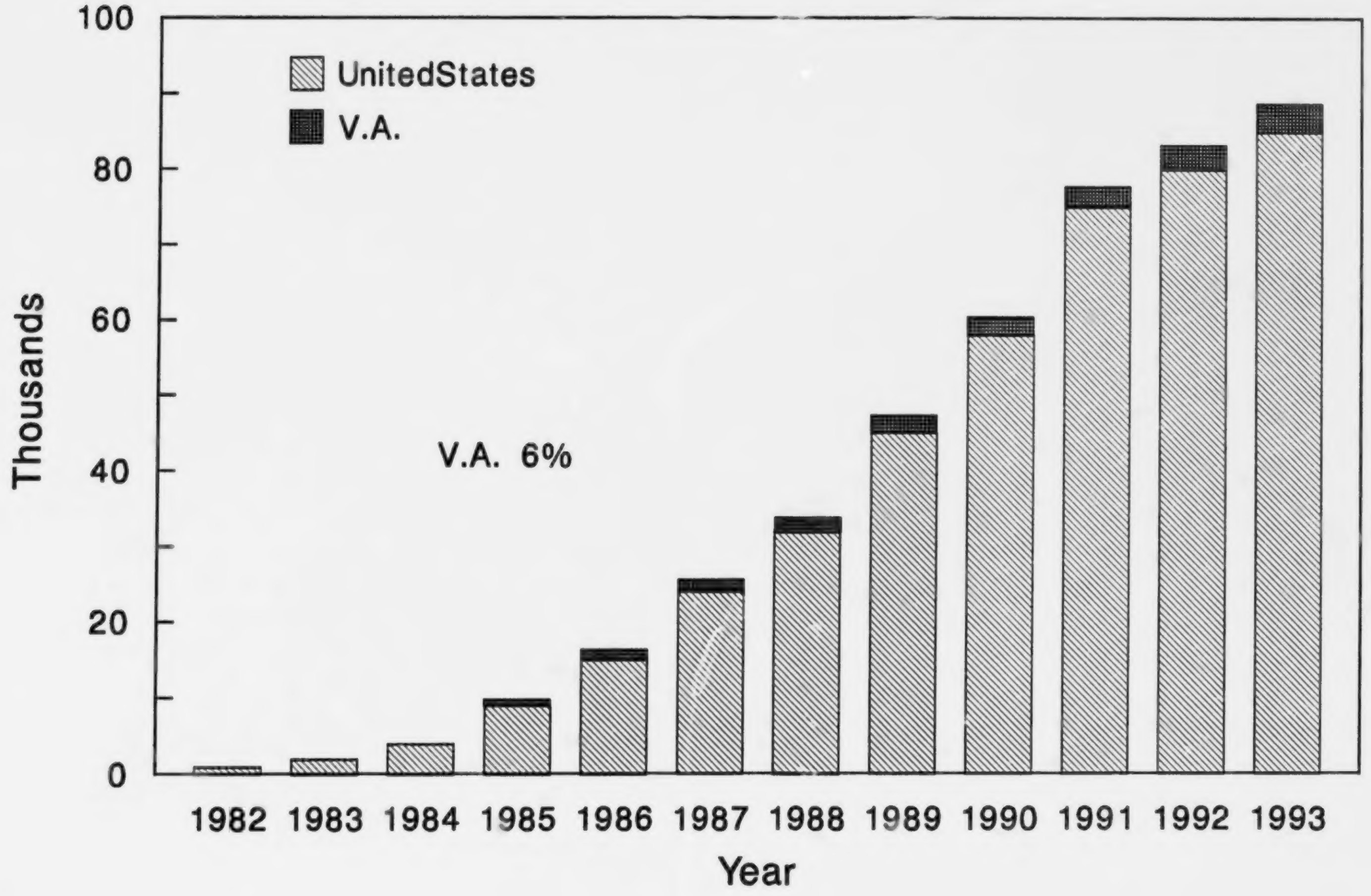
VA Aids Registry

Sex



December 31, 1989

Projected Cases of Aids



21. Breslow NE, Day NE, Halvorsen KT, Prentice RL, Sabai C. Estimation of multiple relative risk functions in matched case-control studies. Am J Epidemiol 1978; 108:299-307.
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26. Pearson Murphy BE. Human fetal serum cortisol levels related to gestational age: evidence of midgestational fall and a steep late gestational rise, independent of sex or mode of delivery. Am J Obstet Gynecol 1982; 144:276-82.
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MEDICAL PROGRESS

TRANSMISSION OF THE HUMAN IMMUNODEFICIENCY VIRUS

Gerald H. Friedland, M.D., and Robert S. Klein, M.D.

THE likely routes of transmission of the acquired immunodeficiency syndrome (AIDS) were established before an etiologic agent was identified. The appearance of AIDS in disparate populations, connected only by probable routes of transmission, was among the initial pieces of evidence suggesting an infectious cause. First described among homosexual men in June 1981,[1] AIDS was recognized among intravenous drug users and Haitians the following year[2,3] and among recipients of blood or blood products,[4,5] infants born to mothers at risk,[6] heterosexual sexual partners of patients with AIDS,[7] and Africans[8] by early 1983. These populations were clustered into a hierarchy of mutually exclusive "risk groups" for epidemiologic surveillance and reporting purposes during the first years of the epidemic.[9] Although precise analysis of routes of transmission required identification of an etiologic agent, it appeared logical that the presence of AIDS in each of these diverse groups was the result of transmission of an infectious agent by infusion or inoculation of blood, sexual contact, and perinatal events.

The discovery in 1983[10] of the human immunodeficiency virus (HIV), the etiologic agent of AIDS, the recovery of the virus from substantial numbers of patients with AIDS and related conditions in 1984,[11] the presence of antibodies to this retrovirus in populations at increased risk for AIDS,[12] and its inadvertent transmission with subsequent disease production in donor–recipient transfusion pairs[13] have confirmed the earlier hypotheses of specific routes of transmission of an infectious agent. Despite the inexorable spread of HIV infection and disease worldwide, the three routes of transmission initially described still remain the only ones demonstrated to be important (Table 1). This article reviews current information related to the routes of transmission of HIV infection.

TRANSMISSION BY BLOOD

Transfusion of Blood and Blood Products

Persons who have acquired AIDS through the transfusion of infected blood or blood products represent a small but important proportion of the total number of cases. Through January 1987, 2 percent of adults and 12 percent of children with AIDS in the United States were believed to have acquired the disorder in this manner.[14] Transfusion-related AIDS has provided a number of important insights into HIV transmission. First, transfusion-related cases in which AIDS developed in both donor and recipient provided strong support for an infectious cause of the syndrome. Second, these cases clearly implicated blood as an important infected body fluid[13,15] and one that might logically explain transmission patterns in other populations at risk, such as intravenous drug users. To date, whole blood, blood cellular components, plasma, and clotting factors have transmitted HIV infection. No other products prepared from blood (e.g., immunoglobulin, albumin, plasma protein fraction, and hepatitis B vaccine) have been implicated.[16] Third, because of the single point in time of inoculation, as opposed to the probable repetitive exposure over time characteristic of other methods of acquisition, transfusion cases have provided information regarding the likely incubation period of the disease. In the initial studies by Curran et al., the median incubation period was 27.5 months among 18 patients.[13] More recent estimates, based on mathematical modeling, have extended this period to 4.5 years.[17] Fourth, investigation of the likely infectious donors in transfusion-related cases confirmed the existence of a prolonged, asymptomatic but infectious carrier state among persons infected with HIV. This finding is of immense importance in the spread of HIV infection, since, as with other infectious diseases, asymptomatic persons are most likely to transmit infection. Feorino et al.[18] re-

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Table 1. Transmission of HIV Infection.

- Known routes of transmission
  - Inoculation of blood
    - Transfusion of blood and blood products
    - Needle sharing among intravenous drug users
    - Needle stick, open wound, and mucous-membrane exposure in health care workers
    - Injection with unsterilized needle
  - Sexual
    - Homosexual, between men
    - Heterosexual, from men to women and women to men
  - Perinatal
    - Intrauterine
    - Peripartum
- Routes investigated and not shown to be involved in transmission
  - Close personal contact
    - Household
    - Health care workers without exposure to blood
  - Insects

ported that among cases of transfusion-associated AIDS, HIV was isolated from 22 of the 25 donors presumed to be infectious. Recovery of the virus was accomplished from 12 to 52 months (mean, 28) after the infected blood was donated, yet more than 90 percent of donors were still asymptomatic at the time of study.

Information about inoculum size and attack rate has also been provided by investigations of transfusion-related cases. Ward et al.[19] evaluated the recipients of blood from donations made by persons who were subsequently found to have AIDS or HIV antibodies. Of 59 recipients of blood from 31 donors, 39 (66 percent) were positive for HIV antibodies. Infection was more likely if donation occurred close to the time the donor became symptomatic. All transfusions within 23 months of the development of AIDS in the donor led to infection. Once HIV was transmitted to a recipient, all subsequent recipients from 11 donors studied became infected. A single HIV-infected donor may transmit infection to multiple recipients of blood components from a single unit.[20] Thus, it appears that, given a large enough inoculum and an appropriate route, infection may be universal. More precise measures of inoculum size or infecting dose are limited by the circumstances of HIV infection in humans, the difficulties in quantitating virus in vivo, and the unavailability of a suitable animal model apart from the chimpanzee. The minimum dose of virus that can successfully establish infection in humans or chimpanzees is not known.[21]

Finally, transmission of HIV by blood and blood products has demonstrated that it is possible, with concerted effort, to eliminate a route of transmission almost completely. In this instance, it was done by applying a technical solution to what is essentially a technical problem in industrialized countries — the screening of blood and the inactivation of virus in blood products. The screening of donated blood and plasma for antibody to HIV, begun in April 1985,[16] and heat treatment of clotting-factor concentrates coupled with donor screening[22] have reduced the risk associated with transfused blood products to an extremely low level. Although transmission by a seronegative unit of blood has been reported,[23] it is currently estimated that even with a false negative rate of 3 percent with the enzyme-linked immunosorbent assay — a "worst-case scenario" — the risk of infection from a transfused unit of blood is between 1 in 100,000 and 1 in 1,000,000. This remarkable success in interdicting transmission should make future transfusion-associated HIV infection a rare event. However, 70 to 80 percent of persons with hemophilia have already acquired HIV antibodies, and it is estimated that 12,000 persons in the United States were infected with HIV through transfusions before screening of donated blood began.[24] Therefore, we should anticipate additional cases of transfusion-associated AIDS in the next few years as these infected persons become ill. Furthermore, in developing countries, the infrastructure and resources for the screening of transfused blood are limited or rudimentary.[25] Finally, no clear opportunities for the application of such strictly technical solutions to the other means of HIV transmission, which are deeply rooted in patterns of personal and societal behavior, appear possible.

Transmission by Parenteral Inoculation

If a large inoculum of HIV-containing blood given by the intravenous route carries an extremely high risk of infection, it is reassuring to know that a single small inoculum delivered by the parenteral route is associated with a very low risk. This information is derived from studies of accidental needle-stick inoculations among health care workers. Although the exact amount of blood involved in these accidents is not known, experiments indicate that the mean volume of blood inoculated during needle-stick injuries is extremely small (1.4 μl).[26] Isolated anecdotal parenteral exposures resulting in HIV infection have been reported among health care workers,[27-29] as have three substantial exposures of either mucous membranes or inflamed, uncovered skin.[30] These instances indicate that the time to seroconversion is one to three months. They clearly demonstrate the possibility of transmission by HIV-infected blood. However, they do not provide a rate of risk, because the at-risk population is not known.

The most useful data on such risk is derived from studies involving large numbers of health care workers who received accidental parenteral or mucous-membrane inoculation. Through July 1987, 770 health care workers (physicians, nurses, respiratory therapists, and laboratory personnel) were evaluated in five published studies (Table 2).[31-35] When subjects at risk for HIV infection through nonoccupational exposure were excluded, only three subjects were shown to have antibodies to HIV. In only one instance was seroconversion related to a known exposure event documented by blood samples obtained before and afterward. This case involved the accidental deep intramuscular injection of a substantial quantity of blood.[28] Thus, the rate of acquisition of HIV infection

Table 2. Studies of the Risk of HIV Infection Associated with Parenteral or Mucous-Membrane Exposure.

Study	No. of Subjects Tested	No. of Subjects Positive	No. Positive without Other Risk Factor
Hirsch et al.[31]	33	0	0
Weiss et al.[32]	42	1	1
Henderson et al.[33]	150	0	0
Gerberding et al.[34]	94	0	0
McCray et al.[35]	451	2	2
Total	770	3	3

is 1.3 to 3.9 per 1000 health care workers with parenteral exposures. The most precise risk data come from the prospective studies by Henderson et al.,[33] and by McCray et al.[35] In the former, among 124 persons from whom a second specimen was obtained more than 90 days after the exposure event, the rate of risk was 0.5 percent (upper 95 percent confidence limit, 1.65 percent). In the latter study, there were 150 cases of exposure (in which repeated serologic tests were done at least six months after the exposure) without infection — a risk of zero (upper 95 percent confidence limit, 2.0 percent). Combining all studies of documented percutaneous or mucous-membrane exposure in which preexposure or contemporaneous serum samples were available indicates that the upper 95 percent confidence limit for the risk is 0.76 percent.[33] This can be contrasted with an incidence of seroconversion of 12 to 17 percent after accidental percutaneous injection of blood or serum from patients who are positive for hepatitis B surface antigen, even after passive immunization of recipients by immune serum globulin.[36,37]

These single-exposure studies demonstrate that inoculum size is important in determining the risk of HIV infection. Although occupational infection through needle stick occurs, the risk is low. Forty percent of the needle-stick injuries and two of the three nonparenteral exposures resulting in HIV infection could have been prevented if existing guidelines had been followed.[30,35] Adherence to established precautions for hospital and laboratory staff remains of great importance.[38] In contrast, in Third World countries, an appreciable continuing risk of transmission by parenteral exposure may exist. Among adults and children in Haiti and Africa, there is an apparent association between AIDS and medical injections.[25,39,40] Injections for medical or ritual purposes are often administered by untrained practitioners, disposable equipment is not available, and sterilization practices are often inadequate.[25]

TRANSMISSION BY INTRAVENOUS DRUG USE

Intravenous drug use has an important role in the transmission of HIV infection in the United States and Europe. Twenty-five percent of all cases of AIDS in the United States have occurred in persons who use intravenous drugs, and 17 percent have occurred among those in whom intravenous drug use is the only risk factor.[14] In the United States, both AIDS and high rates of HIV infection among intravenous drug users have remained geographically clustered. Eighty-two percent of cases of AIDS among intravenous drug users have occurred in the New York City metropolitan area,[41] where half the nation's estimated 350,000 to 400,000 intravenous drug users are believed to reside.[42,43] In other cities with considerable numbers of intravenous drug users, available seroprevalence studies indicate consistently lower rates of HIV infection than those in New York,[44-46] whereas the prevalence rates in many European cities are similar to those in New York City.[47-49] In addition to the present and anticipated burden of HIV-induced disease among intravenous drug users themselves is the fact that this population occupies a pivotal position in the AIDS epidemic because it represents the principal bridge to other adult populations through heterosexual transmission and to children through perinatal transmission. Ninety percent of intravenous drug users are heterosexuals and 30 percent are women, of whom 90 percent are in their childbearing years.[43] In addition, 30 to 50 percent of female intravenous drug users have engaged in prostitution.[42,43] Thus, intravenous drug users represent the largest pool of HIV-infected heterosexuals in both the United States and Europe. In addition, female intravenous drug users and sexual partners of male intravenous drug users represent the largest number of HIV-infected women of childbearing age, so that there is a direct association of perinatal transmission of HIV and pediatric AIDS with intravenous drug use.[50]

The study of intravenous drug users has been difficult. Incomplete information exists about rates of risk and risk factors associated with the acquisition and progression of HIV infection. The illicit nature of intravenous drug use is woven into a pattern of inner-city poverty and minority racial and ethnic status and is characterized by a lack of community organization and advocacy and an episodic relationship with the health care system. Nevertheless, preliminary information about risk factors associated with HIV infection has been acquired.[44,46,47,51-53] The importance of the sharing of unsterilized needles and syringes contaminated with blood containing HIV is supported by anecdotal and epidemiologic studies, although direct documentation of transmission in this manner has not been possible. Needle sharing was known to occur among intravenous drug users in past decades. The ubiquity and patterns of needle-sharing behavior among intravenous drug users in New York City were documented early in the AIDS epidemic.[51] The practice appears to be equally common among heterosexual and homosexual intravenous drug users, providing a logical link for transmission between the two populations at highest risk in New York City.

After purchase, drugs in powdered form are commonly placed in a bottle cap "cooker." The powder is then diluted in tap water, heated to go into solution, and withdrawn into a needle and syringe. A suitable vein is identified and punctured, blood is withdrawn into the needle and syringe, and the solution is injected. Often, small quantities of drug are injected repeatedly, with intervening blood withdrawals. Thus, the injection apparatus, or "works," is easily contaminated with blood. Needles, syringes, and "cookers" are all shared. It is common practice to rent a used needle in a "shooting gallery," where intravenous drug users gather to administer drugs. After use, the contaminated "works" are rented to another user. The needle and syringe may be rented repeatedly until they are no longer usable. Thus, sequential anonymous sharing of blood-contaminated needles and syringes occurs among large numbers of persons. It would be difficult to design a system better suited to promote the transmission of a blood-borne infection.

Studies in California and New Jersey have related HIV seropositivity to semiquantitative measures of the amount of needle sharing and the numbers of persons with whom needles were shared.[44,46] More recently, HIV seropositivity has been directly related to the numbers of injections, the number of days of use of unsterilized needles, and the median number of injections in "shooting galleries," rather than to the type of drug used or the duration of drug use.[53] Although the risk of transmission may vary according to the portal of administration, experiments indicate that the amount of infected blood shared during drug use with contaminated equipment is probably very small and similar to the amount in accidental needle-stick inoculations.[26] However, episodes of injections by individual drug users may number in the thousands. Thus, it appears that HIV infection among intravenous drug users is related to repeated exposures to small amounts of contaminated blood through the common practice of sharing contaminated injection equipment.

The personal and societal ills that result in illegal intravenous drug use are not amenable to quick or simple solutions. However, education about HIV transmission, increased availability of treatment for drug abuse, and programs focusing on interrupting high-risk needle-sharing practices by the provision of sterile needles and needle-cleaning kits may reduce the risk of transmission in intravenous drug users.

SEXUAL TRANSMISSION

HIV is fundamentally a sexually transmitted virus, which is transmitted by both homosexual and heterosexual sexual activity. AIDS was first described among homosexual men in 1981.[1] In the United States, gay men remain the largest group at risk and are associated with AIDS in the public mind. At this writing, 74 percent of the U.S. adults reported to have AIDS have been homosexual or bisexual men, of whom 8 percent have also been intravenous drug users.[6] The first evidence for heterosexual transmission was reported in early 1983.[54] Since then, numerous studies in Africa, Haiti, and the United States have made it clear that heterosexual sexual transmission is probably the leading route of HIV infection worldwide and is increasingly important in the United States.[25,39,55-62] All available data support the view that heterosexual transmission is of dominant importance in Africa, the Caribbean, and other Third World areas. First, homosexuality and intravenous drug use are reported to be unusual in Africa.[25] More directly, the distribution of cases according to age and sex provides a persuasive argument favoring heterosexual sexual transmission. The male:female ratio of cases of AIDS and HIV infection is approximately 1:1 in Africa, as compared with 13:1 in the United States, and the age distribution of affected persons is that of a classic sexually transmitted disease, occurring predominantly among young adults and infants. Furthermore, female patients with AIDS are generally younger than male patients and are usually unmarried. In addition, case–control studies show a significantly higher number of heterosexual partners among persons with AIDS as compared with controls, and male patients have sexual activity with prostitutes significantly more frequently than do controls.[63,64] Finally, there is an increased rate of HIV seropositivity among men visiting clinics for the treatment of sexually transmitted diseases, as well as high rates of seropositivity among prostitutes.[55,64] The massive population shifts that have occurred in African nations during the post-independence decades have resulted in increasing urbanization and prostitution and may have facilitated the rapid spread of infection.[25]

Heterosexual transmission is currently of less quantitative importance in the United States. However, the proportion of AIDS cases in this country that are attributable to heterosexual transmission is increasing more rapidly than the proportion of cases in any other category of risk.[61] In 1985, 1.7 percent of adult cases of AIDS reported to the Centers for Disease Control were acquired through heterosexual sexual activity. Projections suggest that by 1991, heterosexual transmission will account for 5 percent of adult cases (3700 patients). If one adds to these cases those in persons born outside the United States, in areas where heterosexual transmission is thought to be the predominant method of transmission (such as Haiti and Africa) and those in persons with no identifiable risk, most of whom are thought to have become infected from heterosexual transmission, the projected proportion of cases resulting from heterosexual transmission will approach 10 percent by 1991.

Heterosexual transmission is not uniformly distributed in the United States. Most cases have occurred in the New York metropolitan area and in Florida. In addition, there is an overrepresentation of members of minority groups among heterosexual cases. The presence of AIDS in women reflects heterosexual transmission, since approximately 30 to 50 percent of women with AIDS have become infected through heterosexual sex.[62] When adjusted for population size in a comparison with whites, the rates of AIDS are 11 to 13 times higher among black and Hispanic women.[50] These variations in rates according to geography and ethnic background reflect the link between heterosexual transmission and intravenous drug use. Among women who have acquired AIDS sexually, five times as many have been sexual partners of intravenous drug users as of bisexual men.[50] Although sexual partners of bisexual men are at risk, it is currently in areas of high prevalence of intravenous drug use that the highest risk of heterosexual transmission exists in the United States.

These domestic epidemiologic data are based on reported cases of AIDS. Since the incubation period of AIDS is prolonged, these cases reflect transmission that occurred years ago. To determine current patterns of heterosexual transmission, seroprevalence data on populations at risk are essential. Unfortunately, the available data are incomplete. Rates of infection among female prostitutes in Central and East Africa are high and appear to be related to sexual activity only.[25,55] In contrast, the chief risk factor for HIV infection in prostitutes in the United States is not sexual practice but intravenous drug use.[65] No information related to the risk of acquisition of HIV infection from prostitutes in the United States currently exists. The experience of the Department of Defense in screening applicants for military service may have the most relevance to the issue of heterosexual transmission.[66] Data obtained on more than 300,000 applicants between October 1, 1985, and March 31, 1986, show a clear difference in seroprevalence related to geographic area. The overall U.S. rate is 1.6 per 1000, whereas the New York City rate is 10.3 per 1000 — 6.4 times the national figure. Most important, there are similar rates among young men and women — 10.6 and 8.3 per 1000, respectively.[67] Unfortunately, no reliable information exists about the risk behavior among persons who are seropositive, and we do not know whether selection bias may influence these rates. Although exposure through intravenous drug use has not been ruled out, the high rates of infection among young women suggest that heterosexual transmission may be occurring at a substantial rate in certain urban areas in the United States.

More detailed seroprevalence information, rather than data from transmission events that may have occurred five years ago, is needed to determine the current magnitude of the problem of heterosexual transmission. Nevertheless, reasonable conclusions from the above information are that heterosexual transmission may be substantially increased at present as compared with five years ago and that its occurrence is highest in geographic areas in which drug use is common, in minority populations, and in young adults.

Risk of Sexual Transmission

The risk of acquiring HIV infection from a single or several sexual encounters with an infected person is not known. Other sexually transmitted diseases, such as syphilis and gonorrhea, carry a substantial risk from a single encounter,[68] which increases with repeated encounters.[69] Available information suggests that HIV is less easily transmitted. A range of risk in prolonged sexual relationships can be derived from several studies examining the steady heterosexual partners of patients with AIDS. In most of these studies, couples were engaged in long-term relationships, often extending over years and involving hundreds of sexual encounters. The overall rate of seropositivity among these steady heterosexual partners ranged from 7 to 68 percent.[56-60,70,71] Although the risk of transmission is substantial in all populations, it is reassuring that most regular sexual partners remain uninfected.

Attempts have been made to define types of sexual behavior or other factors that are associated with seropositivity. Among homosexual men, studies have consistently reported an association between seropositivity and the number of sexual partners, as well as the practice of anal-receptive intercourse.[72-74] Among heterosexuals as well, there appears to be a relation between infection and the number of sexual partners.[55,63] However, it has not been possible to demonstrate an association between seropositivity and the length of the sexual relationship or the number of sexual encounters with each partner. Furthermore, there is inconclusive information associating specific practices and seropositivity. Seroconversion among initially seronegative partners was associated with oral sex in one study.[56] Anal intercourse is clearly not required for transmission between heterosexuals, although it may increase the risk; most seropositive heterosexuals have not engaged in this practice.[55,56,58,71] The inability to detect a consistent association between seropositivity, the length of relationships, the number of sexual encounters, and specific sexual practices suggests that there may be important biologic determinants of infection. Preliminary observations indicate that individual host susceptibility factors,[75] variations in infectivity among different viral strains,[76] or both may be important.

That transmission from men to women occurs is well accepted. The majority of cases attributed to heterosexual transmission in the United States are in women, and the epidemiologic aspects of transmission in Third World countries support the existence of male-to-female spread. Further support is provided by the isolation of HIV from semen[77] and a report of transmission by semen alone through artificial insemination.[78] In a chimpanzee model, it has been possible to transmit HIV infection by applying virus to the vaginal mucosa but not to the oral mucosa.[79] Finally, the sexual-partner studies described above clearly demonstrate substantial male-to-female transmission. The frequency of occurrence of female-to-male transmission remains controversial. In Africa, female-to-male transmission is well documented,[25] whereas in the United States, female-to-male transmission has been reported infrequently. There are two possible explanations. First, transmission from women to men may be less efficient than that from men to women.

Second, the infrequent documentation of transmission of HIV from women to men may be a function of the history of the AIDS epidemic in the United States. Because of the prolonged incubation period of AIDS, cases that are now reported are the result of transmission events that occurred years ago, at a time when the virus was circulating predominantly among the male population — in homosexual and bisexual men, intravenous drug users (of whom 70 to 75 percent are men), and in persons with hemophilia. During this time, the number of infected women was low, and therefore the possibility of female-to-male transmission was small. Furthermore, nearly all the infected women at that time were intravenous drug users. The regular sexual partners of these women often also use drugs, and any infection among them would be attributed to intravenous drug use. With an increase in the pool of infected women, female-to-male transmission may become more common and more easily documented. The transmission of other sexually transmitted diseases is bidirectional. As noted above, the epidemiologic aspects of HIV infection in Third World countries strongly support the existence of female-to-male transmission. The virus has been isolated from the vagina,[80,81] although transmission by vaginal fluid has not been proved. Moreover, anecdotal cases of clear-cut female-to-male transmission have been reported.[82,83] The frequency of sex with female prostitutes has been associated with AIDS among African men.[25,55,64] Finally, in the sexual-partner studies discussed above, small numbers of seropositive male partners of women with AIDS have been identified, with rates of transmission similar to those occurring from men to women.[56,58,60]

The future direction and magnitude of heterosexual transmission in the United States are not known. If the experience in Africa is applicable to this country, substantial increases in heterosexual transmission must be anticipated. However, cultural, behavioral, and environmental factors may make the African experience not directly transposable.

Reduction of sexual transmission of HIV is confounded by the universality of sexuality and its deeply rooted personal and cultural practices. Reduction of transmission requires fundamental changes in behavior, which may be difficult to accomplish. However, it may be possible to make sex safer in terms of disease transmission. The history of sexually transmitted diseases offers some insight into the problem.[84] Past experience suggests that rather than attempting to eliminate sexuality, we should direct our energies to minimizing the risk of transmission during sex. Education about disease transmission, a reduction in the number of sexual partners, the elimination of such high-risk practices as anal intercourse, and provision of condoms are currently available methods of reducing risk. Condoms have been shown to prevent the passage of herpes simplex, cytomegalovirus, and HIV in a series of small in vitro studies.[85,86] Preliminary data from epidemiologic studies have demonstrated an association between condoms and a reduced rate of infection among sexual partners in Florida[56] and prostitutes in Zaire.[87] It is reasonable to assume that the use of condoms will reduce the transmission of HIV during sexual intercourse. Hence, their widespread use may substantially slow the spread of HIV by sexual transmission.

The availability of information about the sexual transmission of HIV has clearly been associated with changes in sexual practice among homosexual men, as evidenced by the decrease in the rates of rectal gonorrhea.[88] However, because of the increasing rate of HIV seropositivity in the population, the risk of acquisition of HIV infection has not lessened.[89] Since the prevalence of HIV infection among heterosexuals who are not intravenous drug users is undoubtedly lower than that among homosexual men, a window of opportunity exists. Specific information about reducing the risk of sexual transmission should be readily available to the entire population. Although there is some risk to all heterosexually active men and women, the highest risk of heterosexual transmission currently appears to be that among young men and women in areas where intravenous drug use is prevalent. A reduction of HIV transmission among intravenous drug users may result in a decreased secondary risk of sexual transmission. However, it is crucial to reach this population with useful and practical information on sexual risk reduction provided in a format and language that is culturally acceptable and effective in influencing behavior.

PERINATAL TRANSMISSION

Precise information on the risk and routes of perinatal HIV infection is lacking. In both the United States and Third World countries, the majority of documented cases of AIDS and HIV infection in infants and small children have occurred as a result of maternal-to-offspring transmission of infection during pregnancy or the perinatal period.[25,90] In the United States, 80 percent of children with AIDS are known to have a parent who has AIDS or is at risk of the disease and presumably infected with HIV.[14] Since pediatric AIDS is so closely linked to maternal infection, it is not surprising that its demographic features in the United States parallel those of AIDS in women and are closely tied to intravenous drug use. Most cases have been reported in New York, New Jersey, and Florida, and the overall cumulative incidences in black and Hispanic children are 15.1 and 9.1 times the incidence in white children.[50]

HIV may be transmitted from infected women to their offspring by three possible routes: to the fetus in utero through the maternal circulation, to the infant during labor and delivery by inoculation or ingestion of blood and other infected fluids, and to the infant shortly after birth through infected breast milk. Presumably, in an individual infant, infection may occur by one or all of these routes, but the relative efficiency and frequency of each route is not known. Only intrauterine and postnatal transmission have been documented. The existence of intrauterine infection is supported by infection in a child delivered by cesarean section,[91] the isolation of HIV from cord blood,[92] and the description of a characteristic facial malformation in 20 infected infants, suggesting that infection occurred between the 12th and 16th week of gestation.[93] A single case of an infant who apparently acquired infection postnatally has been described.[94] In this instance, the mother was uninfected before delivery, but acquired the infection from a postpartum blood transfusion. HIV may be present in the breast milk of infected women.[95] Because the mother breast-fed the infant for six weeks, this was considered to be the likely route of transmission.

The rate of perinatal transmission is not known. Available information indicates that it may be substantially less than 100 percent. Given the large at-risk population of women who are intravenous drug users and steady sexual partners of intravenous drug users, their high fertility rate and rate of HIV infection, and the putative shorter period of asymptomatic infection in infants, substantially more cases of pediatric AIDS than have been reported would have been expected if the rate of transmission approached 100 percent. More directly, uninfected as well as infected infants have been born to mothers who have previously borne an infected child.[96] Finally, preliminary information from studies of pregnancy outcome among known seropositive women reveals a wide range of rates of infant infection, from zero to 65 percent.[96-98] A rough estimate of a 40 to 50 percent rate of perinatal transmission is reasonable on the basis of currently available information.

ROUTES INVESTIGATED AND NOT SHOWN TO BE INVOLVED IN TRANSMISSION OF HIV

Insects

Three areas of evidence support the view that insect-borne transmission of HIV does not occur. First, the age-specific rates of HIV infection and disease[14,25] provide a powerful argument against spread by insects. Insects do not discriminate according to age in their biting habits. In all geographic areas in which AIDS occurs, most cases are in persons aged 20 to 49 years, a classic age-specific distribution for a sexually transmitted disease. Second, detailed epidemiologic investigation of the patterns of HIV infection and risk-related behavior in Belle Glade, Florida, a community receiving national media attention because of its high rates of AIDS and in which arthropod-borne transmission was hypothesized, has made it clear that sexual activity and intravenous drug use were responsible for the observed patterns of infection.[99] In addition, serologic testing indicated that HIV-infected persons were not more likely than others to have been exposed to arthropod-transmitted diseases. Finally, despite reports in the press,[100] there is no biologic evidence to support the presence of HIV in insects.

Close Personal Contact

Health Care Workers

Available surveillance studies demonstrate a low occupational risk for AIDS among health care workers. As of May 1, 1986, 5.5 percent of all patients with AIDS in the United States reported that they were employed in health care or clinical laboratory settings.[101] Since health care workers represent 5.4 percent of the work force, they do not make up a disproportionate percentage of AIDS cases. Ninety-five percent of health care workers with AIDS have reported nonoccupational high-risk behavior. The proportion of all patients with AIDS with no identified risk-related behaviors is 5 percent — the same as that among health care workers. A seroprevalence survey of hospital workers in Zaire demonstrated similar rates of infection among medical, administrative, and manual workers (6.5, 6.4, and 6.0 percent, respectively).[102] Seropositivity was not associated with patient, blood, or needle contact in the work place. Published reports of seroprevalence surveys performed in the United States (Tables 2 and 3) show that more than 1600 hospital workers have been variously exposed to patients with AIDS or potentially infected body fluids, without providing definite evidence of occupationally associated transmission of HIV unless direct parenteral inoculation of infected blood occurred.[31-35] Among 837 subjects without known parenteral or mucous-membrane exposures, only 1 was found to be positive (Table 3). The epidemiologic evaluation of risk in this subject was incomplete. Isolated case reports suggest that noninoculation parenteral exposure carries a small risk in unusual circumstances.[30,103,104] In one instance, a mother caring for a congenitally ill infant acquired infection after daily exposure to the infant's blood, bloody feces, and other body fluids over a prolonged period during which she took no precautions.[103] In other instances, substantial exposures of unprotected skin and mucous membranes to blood oc-

Table 3. Studies of the Risk of HIV Infection Associated with Exposure to Patients with AIDS or Specimens from Such Patients.

STUDY	NO. OF SUBJECTS TESTED	NO. OF SUBJECTS POSITIVE	NO. POSITIVE WITHOUT OTHER RISK FACTOR
Hirsch et al.[31]	85	0	0
Weiss et al.[32]	359	8	2*
Henderson et al.[33]	442	2	0
Gerberding et al.[34]	270	0	0
Total	1156†	10	2

*Includes one subject in whom accidental parenteral inoculation of material from a patient with AIDS occurred and one in whom the epidemiologic investigation was incomplete.

†Includes 319 subjects with accidental parenteral or mucous-membrane exposure to body fluids of patients with HIV infection (included in Table 2) and 837 subjects without such exposure.

curred.[30] These isolated reports must be placed in the perspective of the large cumulative experience among hospital workers indicating lack of transmission.

Nonsexual Household Contact

Of the more than 30,000 cases of AIDS in the United States reported to the Centers for Disease Control by February 1987, none have occurred in family members of patients with AIDS, unless the members have had other recognized risk-related behavior. More direct and precise risk information can be derived from a number of studies in which nearly 500 family members of patients with AIDS were evaluated for evidence of infection[56,57,105-110] (Table 4). The index patients with AIDS have included intravenous drug abusers, homosexual and bisexual men, recipients of blood transfusions, persons with hemophilia, and others. These studies failed to demonstrate a single HIV infection among household members who did not have additional exposure to HIV infection through blood, sexual activity, or perinatal transmission. Combining these negative studies reveals an upper 95 percent confidence limit for risk of 0.64 percent. An additional household study performed in Africa has supported these findings; there was no significant difference in the rate of HIV infection among family members of patients with AIDS and that among family members in control households.[111]

An examination of the type, duration, and frequency of contact within the household offers additional important information on the lack of household transmission. These issues have been most carefully characterized in two studies performed in families of adults and children with AIDS, respectively.[105,106,110] Household members were defined as nonsexual partners living with a patient for at least three months during a period of presumed infectivity, beginning 18 months before the onset of symptoms.

In the first study the median duration of household contact during the period of presumed infectivity was almost two years. No specific precautions were taken in the household, since most interaction took place before the diagnosis of AIDS was made. For the majority of the members of the household, the time from the initial contact with the index patient during the period of presumed infectivity to the time of the last evaluation was 36 months. Therefore, a sufficient period had elapsed for seroconversion to have occurred. The majority of household contacts shared household facilities, including beds, toilets, bathing facilities, and kitchens, as well as items likely to be soiled by patients' saliva or body fluids (e.g., eating utensils, plates, drinking glasses, and towels). The clothing of the patients with AIDS and that of the family members were washed together in most households. In addition, many household members helped the patients to bathe, dress, and eat. Finally, personal interactions expected of family members, including hugging, kissing on the cheek, and kissing on the lips, took place with great frequency. Despite this substantial close exposure over a prolonged period, none of the household contacts had evidence of infection, except one child born to a mother with AIDS. Illness early in the life of this child suggested perinatal transmission. The risk of HIV transmission through household contact in this study was zero (95 percent confidence interval, 0 to 2.06 percent).

A second study evaluated 86 family members of 24 children with AIDS. No transmission of HIV was demonstrated after similar close interactions, which in this study included occasional biting of siblings by the index children.[106] Furthermore, there has been a report of an adult patient with AIDS who bit 30 health care workers without resultant HIV transmission.[112]

Body Fluids

HIV has been isolated from blood,[10,11] semen,[77,113] vaginal secretions,[80,81] saliva,[114,115] breast milk,[95] tears,[116] urine,[117] serum,[118] cerebrospinal fluid,[119] and alveolar fluid.[120] Only blood and semen have been directly implicated in transmission,[13,78] and transmission by vaginal fluid and breast milk probably occurs. The isolation of virus from a body fluid does not necessarily mean that the fluid is important in transmission. Nevertheless, the issue of transmission by saliva remains worrisome in the public mind. In the household studies described above, many items soiled by saliva were shared by family members without transmission. The risk of transmission by saliva is also addressed in epidemiologic studies of dental workers with continuing exposure to saliva as well as blood. Preliminary studies of hundreds of dental workers, many of whom cared for patients with AIDS

Table 4. Studies of the Risk of HIV Infection among Household Contacts of Patients with AIDS.

Study	Index Patients*	No. of Index Patients	No. of Household Contacts	No. Positive	No. Positive without Other Risk Factors
Saltzman et al.[110]	Adults (IV drug users)	61	145	1	0
Rogers et al.[106]	Children (transfusion recipients)	24	85	0	0
Fischl et al.[56]	Adults (Haitians, IV drug users)	45	138	19	0
Redfield et al.[57]	Adults (heterosexuals, IV drug users)	7	11	1	0
Thomas et al.[107]	Women	28	25	3	0
Lawrence et al.[108]	Adults and children (hemophiliacs)	29	42	0	0
Jason et al.[109]	Adults and children (hemophiliacs)	34	45	0	0
Total		228	491	24	0

*IV denotes intravenous

or persons at increased risk for HIV infection, have shown no evidence of transmission.[34,121] Although HIV has been isolated from saliva, the rate of isolation of virus from the fluid must be appreciated. For example, in one study of 71 men infected with HIV, the virus could be recovered in 28 of 50 samples of blood but in only 1 of 83 specimens of saliva.[115]

HIV is easily inactivated by simple and readily available physical and chemical agents, including household bleach in a 1:10 dilution, alcohol, hydrogen peroxide, paraformaldehyde, Lysol, and heat (56°C for 10 minutes).[122]

CONCLUSIONS

The accumulated data strongly support the conclusion that transmission of HIV occurs only through blood, sexual activity, and perinatal events. Nevertheless, the fear of transmission by other routes may continue to increase with the anticipated increase in the number of cases of AIDS over the next few years. An unrealistic requirement for absolute certainty about the lack of transmission by other routes persists, despite the knowledge that it is not scientifically possible to prove that an event cannot occur. It remains difficult to believe that a virus that is spreading rapidly and may cause a cruel, frightening, and fatal disease is not highly contagious and easily transmitted. The available data indicate that HIV transmission is not highly efficient in a single or a few exposures, unless one receives a very large inoculum. The widespread dissemination of HIV is more likely the result of multiple, repeated exposures over time by routes of transmission that are strongly related to personal and cultural patterns of behavior — particularly, sexual activity and the use of drugs. Isolated transmission events should be placed in full perspective by examining the results of population-based studies that provide rates of risk. It is from these studies that rational approaches and public policy should be developed. Although we are confronted by a public health problem of potentially catastrophic dimensions, it is essential to appreciate that unwarranted fears of HIV transmission have compounded the suffering of young men, women, and children infected with HIV and have blunted an appropriate societal response aimed at reduction of transmission. Creative solutions to the problem of transmission by routes that have already been demonstrated and in populations at highest risk for acquisition are our greatest need.

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AIDS AND THE VA: A REPORT FROM THE FRONT LINE

Acquired immunodeficiency syndrome (AIDS) and infection with the human immunodeficiency virus type 1 (HIV-1) constitute a public health concern of major proportions. By the end of 1987, nearly 50,000 cases of AIDS had been reported in the United States; more than half of those individuals have died as a result of the virus. Because of the large number of Americans already infected, morbidity and mortality figures can be expected to climb in the near future.

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As the nation's largest medical system, the VA plays a crucial role in the treatment of AIDS. In November 1987, at a symposium held during the annual meeting of the Association of American Medical Colleges, VA physicians presented data on the disease and projections regarding its impact on the VA medical system and the greater health care community. The statistics quoted have been updated and are accurate as of March 1988.

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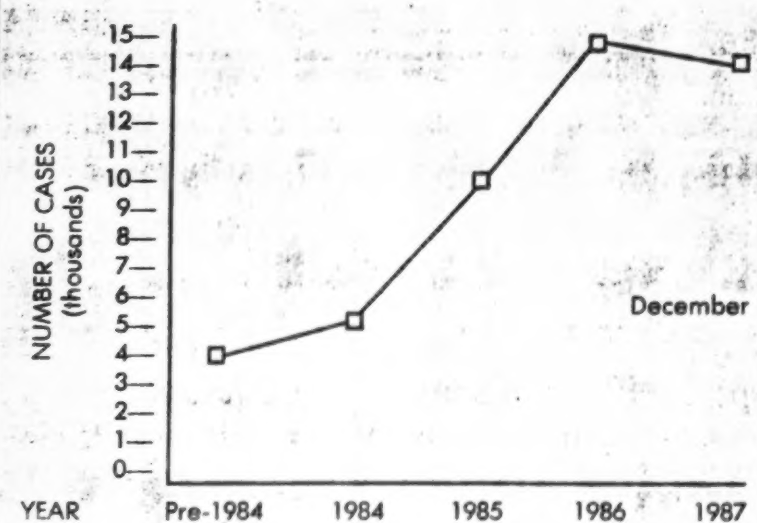
We began the registry of AIDS patients in the Veterans Administration in August of 1983. At that point, 46 medical centers reported having seen 118 patients with AIDS. By the end of 1983, the cumulative number had risen to 211. At that time the United States had seen more than 4,000 patients with AIDS. The following year we saw 189 new patients and the new cases have been increasing since then: in 1985 there were 317; in 1986, 829; and in 1987, 1,927 (Figure 1).

We probably do have at least 85% of AIDS patients reported now, although the 1987 number is somewhat inflated due to increased attention to the recording system. The greater number of cases also may reflect the expanded definition of AIDS since September 1987, to now include the wasting syndrome that the Africans call "slim disease," and dementia.

Although the VA is encountering most of its AIDS cases in the epicenters of the disease—just as you would suspect, with New York and California dominating the picture, cases are also seen at VAMCs on the eastern seaboard and the Gulf coast.

Nine VA medical centers have seen 50% of all the VA's AIDS patients. New York's Manhattan VAMC leads the way: by the end of 1987, there were 411 recorded admissions with a diagnosis of AIDS. Next in line is West Los Angeles; San Francisco, and the Bronx and Brooklyn in New York; East Orange, New Jersey, Houston, and Miami; and San Juan, Puerto Rico. Each of those hospitals has seen more than 100 patients. When we were first concerned with AIDS, we spoke about hospitals that had seen more than 10 patients. Now we are talking about hospitals that have seen more than 100.

Back in 1986, we did a one-day patient census and found there were 136 patients in the hospital at that time. Again, Region I—with centers in the



	Pre-1984	1984	1985	1986	1987
Annual U.S. total	4,181	5,695	10,094	15,014	14,759
Annual VA total	211	189	317	829	1,927
Annual VA percent (average = 6.02%)	5.05%	3.32%	3.14%	5.52%	13.06%

Figure 1: Number of AIDS Cases Reported in U.S.

New York City boroughs of Manhattan, the Bronx, and Brooklyn—led the way. Region VI and Region II were tied for second place, which perhaps reflects a difference in the way patients are cared for on the East and West Coasts; on the West Coast, many more individuals are seen on an outpatient basis. Although every region had some patients, the Midwest had the smallest representation—appropriately, because that's where the lowest prevalence is (Table I).

When we look at what kinds of patients we're seeing at the VA and what the risk factors are, we have found a fair number that fit into the "unknown" or "unreported" categories, which may reflect that patients come in and die or are not in any position to give a good history before the diagnosis is made, or that the information was not available when the form was filled out. Forty-six percent of our patients are bisexual or homosexual and 25% are intravenous drug-abusers; 7% are both (Table II). Three percent are patients who can track the disease down to transfusions, and 2% are heterosexuals who have been exposed to high-risk individuals, such as prostitutes. (In the military, many discharged with a diagnosis of AIDS relate the disease to that kind of exposure.)

In terms of ethnic representation, both in the U.S. in general and in the VA, AIDS is a disease in which blacks and Hispanics are represented out of proportion to their numbers; 46% of VA patients are white, 32% are black, and 11% are Hispanic; Asians and American Indians have the lowest percentages of VA population representation (Table III). This is not a women veterans' issue—only eight of the 3,473 patients in our AIDS registry are female.

There are differences between the East Coast and West Coast patient, and we conducted a "quick and dirty" survey in some of our efforts to find out what it costs to treat an individual with AIDS. We asked nine hospitals to provide information on the last ten patients discharged with AIDS in fiscal year 1986; using that data we came up with these figures for the East Coast versus the West Coast: The patients on the West Coast are slightly older; the average age of the VA AIDS patient is 41 years. Two thirds of the patients on the West Coast were homosexuals, compared to the East Coast on which only 17% were homosexuals (Table IV).

We know that we're seeing increasing numbers of AIDS patients every year and it's not going to get any better in the foreseeable future; 1991 seems to be as far away as anybody wants to predict. Considering the figures that the U.S. is projecting, and the fact that the VA now sees about 6% of those patients, in 1991 the VA will continue to see a significant share of the cases in this country.

In July 1987, Central Office decided that the AIDS issue required an intensified effort. Chief Medical Director (CMD) John Gronvall, MD, took several actions: first, he appointed the AIDS Steering Committee, a group of experts from the field who will meet at least four times a year, with other meetings by phone, and he set up a subcommittee to provide policy guidance. At the same time, Gronvall set up the AIDS Working Group, which I chair, and assigned several people to coordinate day-to-day activities of VA departments and extramural agencies, answer questions from the field, and assess the need for a permanent office.

Four issues, I think, need to be addressed: The first, a big problem in the VA, involves the funding of AIDS care. There is universal agreement that the cost of taking care of an AIDS patient is greater than the reimbursed amounts, although just how much of a gap exists is uncer-

Table I: AIDS patients in VAMC—one-day patient census 10/31/86.

VA Region	Number of inpatients
I	52
II	21
III	10
IV	11
V	6
VI	21
VII	15

tain. Early on, we conducted a survey involving four or five medical centers. The survey asked: How long are patients kept, how many days do they spend in the intensive care unit, and how many outpatient visits do they have? We discovered that it costs about $38,000 annually to take care of a patient who lived for approximately 2.5 years.

As time went on we felt that this figure was inaccurate. The most recent approximation is $25,000 per year to care for the "average" AIDS patient. Out of that $25,000, our stations are probably reimbursed $5,000. So, the cost-overrun for the AIDS patient seems to be about $20,000, but that is a very rough estimate.

The second area of concern is the question of testing. Last spring, President Reagan announced that he planned to have the VA consider routine testing of all VA inpatients for AIDS antibodies. We made up a graph that may explain why the veteran hospital population is really not the place to look for AIDS antibodies (Figure 2). The average age of a hospitalized veteran is about 65; the average AIDS patient is between 35 and 40 years old. So this is not the appropriate population in which to look for AIDS antibodies. The veterans service organizations have also taken umbrage at the President's suggestion of routine testing of veteran patients, because they feel it implies that veterans are more likely to get AIDS than other people.

The problem of false negatives and false positives is a real one. We have already dealt with some discharged service people who were denied reenlistment when they were declared HIV-positive, even though those results were not definitive. At follow-up, it was discovered that they had two negative ELISA readings and one band on the Western blot, which was a very equivocal band, and we would certainly call these individuals HIV-negative. The military, however, chose to interpret the readings as HIV-positive, a decision that certainly affected their service careers and probably their future job marketability.

At the VA, we are not too keen about becoming involved in the mass screening of a low-prevalence group because of the inevitable number of false positives and false negatives. We are getting pressure from groups within the VA. The labor unions are extremely interested in testing and labeling all patients. When you try to explain that those procedures are not possible, they seem to understand but nonetheless assert that they have the right to know who is HIV-positive.

Many surgeons have also expressed a need to know which of their patients are HIV-positive. In some parts of the country, surgeons have indicated they would not operate on someone they knew to be HIV-positive. We have not experienced that problem within the VA although some VA dieners have refused to perform autopsies on HIV-positive individuals. According to VA policy we take care of AIDS patients, and this includes *all* their needs. If this also means an autopsy then we do autopsies on AIDS patients. We provide education about AIDS and any protective devices that we can, but if a diener or pathologist is unwilling to do an autopsy on an AIDS patient, perhaps he or she is in the wrong field.

We are just completing a survey on testing procedures in the VA, and it is somewhat disconcerting to find that 20% of those who responded said they did not get informed consent on all the patients who were tested (this issue has since been addressed in a CMD letter IL10-87-24 and with the individual noncompliant VAMCs). Some people in the VA feel they should not have to ask permission in certain cases, such as in the event of needle-stick injuries. In fact, very few patients have not given permission when they've been involved in such an episode, but if a patient does re-

Table II: Comparison of risk factors in VA and U.S. AIDS patient populations, as of 12/31/87.

Risk factor	VA (%)	U.S. (%)
Homosexual/bisexual	46	65
Intravenous drug abuser	25	17
Homosexual/Bisexual and IV drug abuser	7	8
Hemophiliac	—	1
Heterosexual contacts	2	4
Transfusion	3	2
Unknown/Unreported	15	3

continued

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4/18/85

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Table III: Comparison of ethnic groups among VA and U.S. AIDS patient populations, as of 12/31/87.

Ethnic groups	VA (%)	U.S. (%)
White	46	61
Black	32	25
Hispanic	11	14
Unknown/Unreported	10	1

fuse, testing cannot be done and time should be spent discussing actual risks, doing follow-up blood tests, and letting the employee know that even if the patient is HIV-negative, he can't breathe a complete sigh of relief, as we have learned from blood transfusion misfortunes.

Another issue with which we must deal is confidentiality. This is an important consideration and one that will become increasingly significant as more widespread testing is performed, because in many communities patients who are HIV-positive are viewed with just as much alarm as are those with full-blown AIDS. The most significant factor regarding confidentiality and the one that we are wrestling hardest with is disclosure. Who needs to know and who has the legal right to know HIV or AIDS status?

Certainly, there is universal opinion that AIDS cases must be reported to the health department and to the Centers for Disease Control. However, do cases of HIV *infection* need to be reported? Is there a community benefit to be gained by having lists of HIV-infected individuals available to the public? How will the health department act? Ideally, there would be an intensive education effort to help stop the spread of the disease, and yet we know that most local health departments cannot even treat all the gonorrhea cases in the community, let alone mount intensive education programs for HIV-positive individuals.

Another concern is that many patient records are automated. Computer software carries some very important personal information about human beings which, if released to the public, could have serious effects on their social and economic lives.

The final issue with which we must contend is implementation of universal precautions. Intellectually, we all can agree that barrier protections are essential and that treating all patients as though they were potentially infectious is appropriate. The problem comes when you get down to the nitty-gritty of who needs those gloves, eye shields, masks, and gowns. Should the individuals who empty trash cans be equipped with such precautionary measures?

Recently, I received a call from a worker in a midwestern hospital, who told me that a psychologist had refused to do testing on an HIV-positive patient without donning gown, gloves, mask, or eye shields. I don't know what kinds of psychological tests they perform at that particular hospital, but that does seem to be overkill. I think the message conveyed when that is allowed to happen is that somehow this psychologist knows something the rest of the employees don't. When you give in to this kind of hysteria or fear, you have a lot to follow up on because of the mixed signals you're sending. Implementing precautionary measures in a sensible manner could be a problem for us.

One final thought is a sentiment that does not come from the VA but from Surgeon General C. Everett Koop, and it is something that we can all keep in mind. "You don't get AIDS by holding out a helping hand," he observes.

I think we can be very proud of the helping hands that we have held out to AIDS patients within the VA. I've always felt that if one is unfortunate enough to have a life-threatening or chronic disease, it's infinitely better to be a veteran and to have access to the veterans' health care system, and I believe this is true of AIDS.

MICHAEL S. SIMBERKOFF, MD,

Chief, Infectious Diseases Section at VAMC New York, where one of the first reported AIDS cases was seen.

Those of you who hold senior management positions in the VA have the responsibility of planning for the future, and the future is now. The single message I would like to impart is that all VAMCs are affected by the AIDS problem. Some of you who already have large patient populations are aware of this; others of you may not have many AIDS patients as defined by the Centers for Disease Control, but there could be patients in the hospital who are HIV-infected, and the problems of this group will certainly become more pronounced.

One of the responsibilities of management will be to assure that these individuals are given the best possible medical care, diagnostic evaluation, and treatment by bringing together multidisciplinary teams of medical specialists—surgeons, nurses, social workers, dietitians, therapists, housekeepers—people at every level. It is important to recognize this is not done without some planning, which should begin as soon as possible. A host of issues must be discussed when problems arise, and possibly even before that, to smooth the transition of these patients into the health care system. The sooner medical centers begin the process, the more likely this success.

The point I want to emphasize is that AIDS itself represents the tip of the iceberg. The vast majority of HIV-infected patients meet neither past nor present criteria for the diagnosis of AIDS. Although we can look at AIDS and quantify the number of cases that we've seen in New York or San Francisco, we have to recognize that for every patient with the diagnosis of AIDS there might be 10 to 100 or more HIV-infected individuals in the medical center who may have lesser or no manifestations of the disease, and who therefore represent a problem for the health care system as well as for themselves.

AIDS, by current definition, is a disease that is characterized by the occurrence of malignancy, opportunistic infection, encephalopathy, or wasting syndrome. The definition of AIDS was modified in September of 1987, and I think we're certainly going to be seeing more patients with encephalopathy and wasting syndrome. We know that in the past, many veterans who have been in our hospitals and have even died as a result of these problems had not been reported as having AIDS, because at that time the definition of the syndrome did not include those conditions.

At least 42,000 cases of AIDS have been reported in the U.S., and about 6% of these have been seen in VA medical centers. Practically all facilities have seen at least one case of AIDS and most are probably treating very substantial numbers of individuals with HIV infections whose conditions may not yet have reached the stage of clinical disease that we can call AIDS.

Our first patient at the New York VAMC was an individual with Kaposi's sarcoma who was seen in the medical center in 1979, died within a few months after diagnosis, and was reported as part of our facility's original group of six patients with epidemic Kaposi's sarcoma. Since 1981, progressively larger numbers of AIDS patients are being seen for the first time at the medical center. For example, we saw 39 cases of AIDS in 1983, 55 cases in 1984, 85 cases in 1985, and more than 100 cases in 1986. In 1987, through August, we'd seen 56 patients with AIDS.

This is part of the reporting artifact. Obviously, many of our patients are reported to us after their original diagnosis, and in some instances it takes time for the diagnosis to be established. Therefore, every epidemic curve shows a fall-off in its final phase. I'm confident, unfortunately, that we are nowhere near the end of the rising phase of the AIDS epidemic.

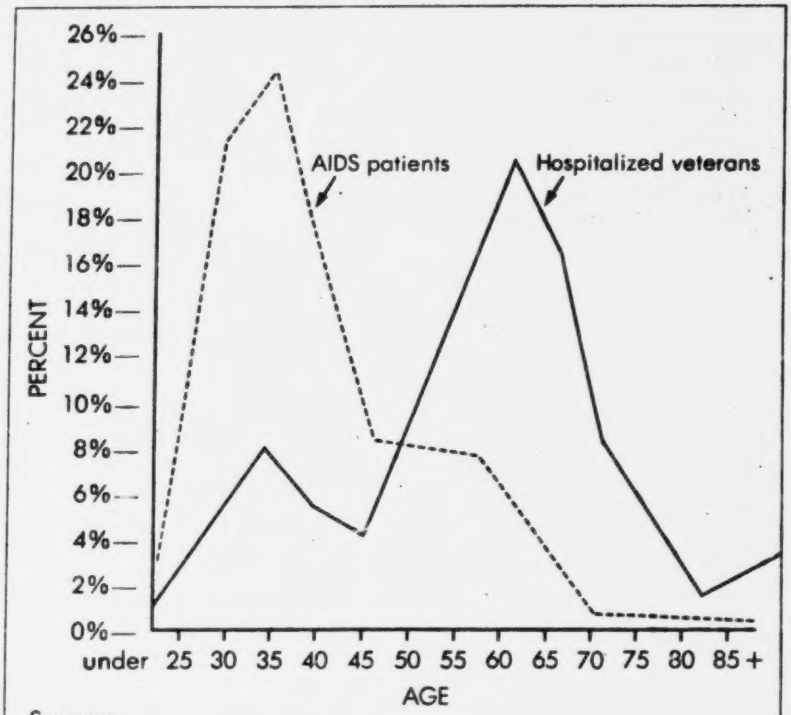
About 43% of AIDS patients at the New York City VAMC were homosexual men; 47% intravenous drug abusers; 3%, individuals who were

Table IV: Geographical variability in AIDS patients.

	Overall	East Coast	West Coast
Average Age	41.2	40.5	43.4
Percent homosexual	36.7	17.5	66.6
Admissions (FY1986)	2.6	2.0	3.1
Length of stay	21.9	27.8	12.4
Outpatient clinic visits	10.2	6.7	17.4

- FY 1986 data
- Survey of 90 patients in nine VA medical centers

continued



Sources:
Hospitalized veterans (1986 VA Annual Report)
VA AIDS patients (2,740 as of 8/31/87)

Figure 2: Age distribution of VA inpatients and VA AIDS patients.

both homosexual and intravenous drug abusers; and about 7%, blood transfusion recipients. Approximately 10% of our patients come to us from other facilities—some from private hospitals after their insurance has been depleted, some from municipal hospitals that did not have sufficient services.

About 3% of our patients have come to us from the Department of Defense (DOD). Management must explore the problem of patients coming directly from there. We exist because of the DOD, and it is our obligation to care for those discharged from the military with non-service-connected illnesses and limited resources. We have a specific duty to take care of the individuals who are discharged from the service with AIDS or HIV-related disease. According to recent data from the DOD, more than 4,000 such patients are now on active duty and many of them will be filtering into the VA health care system in the very near future. It is time for us to start planning the way to smoothly expedite their transfer into our health care system and appropriate facilities, and to manage them the way I think we would all deem proper.

AIDS is a disease that primarily affects the young. Very few of our patients have been in their sixties or seventies, the traditional age groups of our VAMC population. The most tragic fact about AIDS is the mortality of this disease. Overall, the median survival time after onset is between 10 and 11 months. For a group of patients whose average age is less than 40 years, this is a significant curtailment of their life expectancy.

In New York, AIDS is also a disease that predominantly has affected minorities. Almost 70% of our patients have been black or Hispanic; only 30% have been white. Nobody is certain how many HIV-infected individuals there are in the U.S., but reported figures have shown that 4 in 1,000 blood donors in the country are HIV-infected; 1.5 in 1,000 military recruits; from 24 to 68 in 100 homosexual men; and 0 to 61 in 100 drug abusers.

The zero figure is perhaps the most rapidly changing of all the statistics. In California, relatively few drug abusers were infected only a couple of years ago, but now HIV infection is increasing quite dramatically within that group. In New York, well over 60% of intravenous drug abusers are already infected and it is estimated that rate may increase to as much as 60 to 80%, so saturation is already beginning to occur in our intravenous drug-abusing patient subset. Individuals who receive blood transfusions or blood products, and regular heterosexual partners of individuals with AIDS, account for nearly 5% of the nation's HIV-infected population. Anywhere from one to two million individuals may be infected in the United States.

A variety of malignant and infectious complications are seen in AIDS patients. Diagnosis and treatment of these problems require the combined expertise of health care professionals in the disciplines of infectious disease, immunology, pulmonology, gastroenterology, neurology, oncology, neurosurgery, psychiatry, psychology, nursing, dietetics—virtually every area of the hospital is involved in treating these patients. To assemble the care giving teams and to get them to function properly is a formidable task, and I think all of you as VA management should be working to establish groups within your hospitals to facilitate the treatment of these patients.

AIDS patients occupy a significant percentage of the medical beds in facilities such as ours that are located in areas where the disease has become

continued on page 47

prevalent. Throughout 1987, the mean bed occupancy at the New York City VAMC had been more than 20 patients, which is between 15 and 19% of the acute care beds on our medical service. Other facilities have had lesser bed occupancies, but we can anticipate that larger numbers of patients will be seen and we must plan for that.

We have just completed construction of an AIDS unit at our VAMC that will house a number, although not all, of our AIDS patients. This features day hospital care facilities that will be used to treat patients who need transfusions and intravenous therapies but do not require continuous observation. We hope to be able to treat more people on an outpatient basis, and that they will be able to live in the comfort of their homes.

We also hope this will allow us to discharge patients at an earlier date and make acute care beds available for others who are in more urgent need of treatment.

One can divide HIV infection into several stages: initial infection; seroconversion, which occurs within weeks, months, and in rare instances a year or more after initial exposure; a long period of latency during which the patient is utterly asymptomatic but may spread the disease to others; and activation of the virus through mechanisms that are not yet well understood, resulting in thrombocytopenia, progressive generalized lymphadenopathy, or minor opportunistic infections; and finally AIDS itself.

AIDS is caused by the human immunodeficiency virus. We should really be talking about HIV-related disease or HIV infection as well as AIDS, because the individuals who are infected with the virus need our care as much as those who have reached the terminal stages of disease. The tragedy is that progression of HIV infection appears to occur in a high percentage of afflicted individuals. Data presented in June 1987 have shown that in the San Francisco cohort study, 36% of HIV-infected individuals followed for 88 months had developed evidence of the infection's progression to AIDS. It has been estimated that up to 50% of HIV-infected individuals might develop symptoms within ten years of their initial infection.

HIV-testing methods should be available in many facilities. Culture is a rather tedious and expensive way to detect the virus; it is done primarily for research purposes. Detection of antibodies is used far more widely. Usually one combines an ELISA test and Western blot in order to screen and confirm a seropositive individual. The reagents for those tests are commercially available; certainly, performing these tests is well within the technical capacity of virtually every laboratory in the VA system. Also being developed are methods currently used primarily for research purposes to detect viral-specific antigens and virus-specific genome within infected cells.

> *AIDS test results should always be given to the patient in person rather than by letter or telephone*

We recommend that HIV testing be done on a voluntary basis and be accompanied by pre- and post-test counseling. We also feel such testing should be directed primarily toward target populations: homosexual or bisexual men, drug abusers, blood or blood product recipients, all sexual partners of the aforementioned, sexual partners of individuals known to have AIDS or HIV, and children of HIV-infected mothers.

Test results should always be given to the patient in person rather than by way of letter or telephone. News of positivity can be devastating and could mandate a great deal of discussion between the physician and the individual, both initially and then perhaps at later times. Even negative tests must be explained to patients: it must be made clear that patients still might acquire infection if they continue to engage in high-risk behavior.

Test results should be confidential but not anonymous, since the medical knowledge of HIV seropositivity may be very important in making clinical decisions for the management of patients with a variety of illnesses. Medical follow-up should be assured and support services made available to these individuals, who often require social, psychological, and dietary assistance after their HIV-infection has been made known to them.

There is currently only one treatment for HIV infection. I am honored to be the co-chairman of a VA cooperative study that is evaluating zidovudine, formerly known as azidothymidine or AZT, in the treatment of patients who have AIDS-related complex, to determine whether it is effective in preventing the progression of that disease. This study is going on in five medical centers and I think it will be very important not only to the VA but to the medical community as a whole. Other drugs have been advocated for treating HIV infection, but at present none can be used clinically.

Prevention is another critical area for us to consider, and education currently is our most effective weapon against the virus.

PETER C. JENSEN, MD,

Chief, Infectious Diseases Clinics and Assistant Chief, Infectious Diseases Section at VAMC San Francisco, the facility that ranks third in the VA system in number of AIDS patients treated.

California differs from New York in patients that we've seen and approaches to care that we've taken. There's no one right way; each of you within your own geographic areas and

continued

Halcion
Tablets (triazolam) ©

INDICATIONS AND USAGE: HALCION Tablets are indicated in the short-term management of insomnia characterized by difficulty in falling asleep, frequent nocturnal awakenings, and/or early morning awakenings.

It is recommended that HALCION not be prescribed in quantities exceeding a one-month supply.

CONTRAINDICATIONS: Patients with known hypersensitivity to this drug or other benzodiazepines.

HALCION is contraindicated in pregnant women due to potential fetal damage. Patients likely to become pregnant while receiving HALCION should be warned of the potential risk to the fetus.

WARNINGS: Overdosage may occur at four times the maximum recommended therapeutic dose. Patients should be cautioned not to exceed prescribed dosage.

Because of its depressant CNS effects, patients should be cautioned against engaging in hazardous occupations requiring complete mental alertness and also about the simultaneous ingestion of alcohol and other CNS depressant drugs.

Anterograde amnesia and paradoxical reactions have been reported with HALCION and some other benzodiazepines.

PRECAUTIONS: *General*: In elderly and/or debilitated patients, treatment should be initiated at 0.125 mg to decrease the possibility of development of oversedation, dizziness, or impaired coordination. Some side effects, including drowsiness, dizziness, lightheadedness, and amnesia, appear to be dose related.

Some evidence suggests that confusion, bizzare or abnormal behavior, agitation, and hallucinations may also be dose related, but this evidence is inconclusive. It is recommended that therapy be initiated at the lowest effective dose. Caution should be exercised in patients with signs or symptoms of depression which could be intensified by hypnotic drugs. Suicidal tendencies and intentional overdosage is more common in these patients. The usual precautions should be observed in patients with impaired renal or hepatic function and chronic pulmonary insufficiency. *Information for Patients*: Alert patients about: (a) consumption of alcohol and drugs, (b) possible fetal abnormalities, (c) operating machinery or driving, (d) not increasing prescribed dosage, (e) possible worsening of sleep after discontinuing HALCION. *Laboratory Tests*: Not ordinarily required in otherwise healthy patients. *Drug Interactions*: Additive CNS depressant effects with other psychotropics, anticonvulsants, antihistaminics, ethanol, and other CNS depressants. Pharmacokinetic interactions of benzodiazepines with other drugs have been reported, e.g., coadministration with either cimetidine or erythromycin approximately doubled the elimination half-life and plasma levels of triazolam, hence increased clinical observation and consideration of dosage reduction may be appropriate. *Carcinogenesis, Mutagenesis, Impairment of Fertility*: No evidence of carcinogenic potential was observed in mice during a 24-month study with HALCION in doses up to 4000 times the human dose. *Pregnancy*: Benzodiazepines may cause fetal damage if administered during pregnancy. The child born of a mother who is on benzodiazepines may be at some risk for withdrawal symptoms and neonatal flaccidity during the postnatal period. *Nursing Mothers*: Administration to nursing mothers is not recommended. *Pediatric Use*: Safety and efficacy in children below the age of 18 have not been established.

ADVERSE REACTIONS: During placebo-controlled clinical studies in which 1003 patients received HALCION Tablets, the most troublesome side effects were extensions of the pharmacologic activity of HALCION, e.g., drowsiness, dizziness, or lightheadedness.

	HALCION	Placebo
Number of Patients	1003	997
% of Patients Reporting:		
Central Nervous System		
Drowsiness	14.0	6.4
Headache	9.7	8.4
Dizziness	7.8	3.1
Nervousness	5.2	4.5
Lightheadedness	4.9	0.9
Coordination Disorder/Ataxia	4.6	0.8
Gastrointestinal		
Nausea/Vomiting	4.6	3.7

In addition, the following adverse events have been reported less frequently (i.e., 0.9-0.5%): euphoria, tachycardia, tiredness, confusional states/memory impairment, cramps/pain, depression, visual disturbances.

Rare (i.e., less than 0.5%) adverse reactions included constipation, taste alterations, diarrhea, dry mouth, dermatitis/allergy, dreaming/nightmares, insomnia, paresthesia, tinnitus, dysesthesia, weakness, congestion, death from hepatic failure in a patient also receiving diuretic drugs.

The following adverse events have been reported in association with the use of HALCION and other benzodiazepines: Amnestic symptoms, confusional states, dystonia, anorexia, fatigue, sedation, slurred speech, jaundice, pruritus, dysarthria, changes in libido, menstrual irregularities, incontinence and urinary retention.

Other events reported include: Paradoxical reactions such as stimulation, agitation, increased muscle spasticity, sleep disturbances, hallucinations, aggressiveness, falling, somnambulism, inappropriate behavior, and other adverse behavioral effects. Should these occur, use of the drug should be discontinued.

No laboratory changes were considered to be of physiological significance.

When treatment is protracted, periodic blood counts, urinalysis and blood chemistry analyses are advisable.

Minor changes in EEG patterns, usually low-voltage fast activity have been observed in patients during HALCION therapy and are of no known significance.

DRUG ABUSE AND DEPENDENCE: *Controlled Substance*: HALCION Tablets are a Controlled Substance in Schedule IV. *Abuse and Dependence*: Withdrawal symptoms have occurred following abrupt discontinuance of benzodiazepines. Patients with a history of seizures are at particular risk. Addiction-prone patients should be closely monitored. Repeat prescriptions should be limited to those under medical supervision.

OVERDOSAGE: Because of the potency of triazolam, overdosage may occur at 2 mg, four times the maximum recommended therapeutic dose (0.5 mg). Manifestations of overdosage include somnolence, confusion, impaired coordination, slurred speech, and ultimately, coma. Respiration, pulse, and blood pressure should be monitored and supported by general measure when necessary. Immediate gastric lavage should be performed. Multiple agents may have been ingested.

Store at controlled room temperature 15°-30°C (59°-86°F).

Caution: Federal law prohibits dispensing without prescription. B-4-S

Reference: 1. NIMH Consensus Conference: Drugs and insomnia: The use of medications to promote sleep. *JAMA* 1984 251 2410-2414.

Upjohn THE UPJOHN COMPANY
Kalamazoo, Michigan 49001 USA
J-8808
March 1988

patient populations is going to have to take the core material and distill it through your medical center to develop a program that's tailored to the people you see and the staff of your hospital.

We in the VA medical system have a responsibility to provide the type of care that will prevent those with untreatable chronic diseases from turning in desperation to the siren song of the "quick fix." The way to accomplish that is with education and high-quality care.

San Francisco now has recorded almost 5,000 cases of AIDS, which is 35 or 40% of all cases in California, and approximately 9% of all U.S. cases. According to statistics from the city and county of San Francisco, 121 of those AIDS cases were first reported at our hospital. However, according to VA Central Office, the number of cases we've reported is 201.

That 80-case discrepancy makes the important point that 35% of our patients with AIDS as defined by the Centers for Disease Control were first diagnosed and reported elsewhere. This means that some patients come into the VA system after they have exhausted their private resources or have decided that they do not want to reduce their total assets to make themselves eligible for Medi-Cal and treatment in a county hospital. Cases, therefore, are coming to us from San Francisco General Hospital, as well as from the city's private physicians and health maintenance organizations.

Those people have never used the VA before. The distribution is largely a homosexual male population but notably, we have about 3.5 times the incidence of transfusion-associated cases. Although the numbers are small, they indicate that we have older patients who have had many more operations during the high-risk blood bank years—1979 to 1985—and so we must target our educational and counseling efforts to that unique population.

Again, primary AIDS diagnoses are about the same in San Francisco as in

continued

New York: 60% *Pneumocystis carinii* pneumonia, 20% Kaposi's sarcoma, and the usual other cases. Our death data parallel national and, I suspect, everyone else's numbers. Although those are presenting diagnoses, the majority of patients develop many other complications, which is one of the factors that contribute to the high cost of their care.

Our case mortality rates are similar to those you've heard from New York. Overall, we have seen about 70% mortality since our first case in 1981. I've compared and contrasted our age distribution with that of the San Francisco experience and have found that 64% of all the cases in San Francisco occur in individuals *under* the age of 40, whereas 62% of VA cases occur in individuals *over* the age of 40, giving us a slightly different population to target.

As I noted earlier, we have a higher percentage of transfusion cases than does the rest of San Francisco. For the past year we have been participating in the Irwin Memorial Blood Bank Look-Back program to identify individuals who received blood products prior to the initiation of HIV testing in March of 1985, from donors who subsequently were found to be seropositive on retrospective testing or found to have AIDS according to Health Department reporting forms.

When we looked at 43 patients about whom we were notified, we found that in slightly more than half, the blood transfusion was a pre-morbid event. Of the 20-plus patients who were discharged from the hospital, about 10 subsequently died, one from AIDS, and one of the 10 patients still alive is seropositive for HIV. We began our own transfusion surveillance program in the past year. We do the HIV blood test and provide the counseling for the patient, and refer spouses to the Irwin blood bank for the same services.

The San Francisco AIDS programs have been greatly influenced by the community, which is politically, financially, and personally active in seeing that every aspect of this disease is addressed. It is obviously more difficult to find lobbyists among the disenfranchised population of intravenous drug users. Addicts are not members of the mainstream; they have no political organization, so plans for their care are not going to come from the private sector. Instead, these patients will require public support and in some instances, it will fall to the VA hospital system to intervene.

I think it's clear that education is about the only weapon we have now to combat this epidemic, and it is the cornerstone of our program. After grappling with the "integration versus segregation" issue, we decided to integrate HIV patients into the general medical and surgical population. We have found that it is easier to get the educational message across when everyone has had the experience of caring for HIV-positive patients.

We're not dealing with AIDS, a disease; we're dealing with AIDS, a psychosocial problem

As I'll mention later, we use a team approach, which runs into occasional bureaucratic snarls. The VA pigeonholes people according to services and sometimes gets nervous over turf issues as, for example, when an infectious disease doctor wants to hire a social worker just to see AIDS patients. The system needs to acknowledge and perhaps change some of the usual approaches to personnel assignment.

Developing contacts in the community is key for us. Success will vary according to the hospital's location, but community outreach and VA involvement in the community is going to be critical, because no one system by itself can do the whole job of dealing with the AIDS epidemic.

Well, what is the job? Right now all we have to work with is education. If this were any other infectious disease, we would know what to do but we're not dealing with AIDS, a disease; we're dealing with AIDS, a psychosocial problem, one that has overwhelming emotional features.

To be successful, education must be directed toward not only the patients themselves but toward individuals in the hospital who are very much concerned about working with AIDS patients. You've also got to deal with family members, either standard biologic family members or the "significant others" who might be the sole support system for patients, especially in the gay community in which individuals are often estranged from relatives.

You've got to work with the support services, from the administration on down. You've heard the recommendations to get dietitians and building management and engineering people involved. The same must be said for the professional staff, frequently believed to be omniscient in all things medical. It is dangerous to assume that everyone is as well-informed as the one or two physicians in your hospital who have followed the AIDS epidemic. If you forget to talk to the psychiatrists, forget to talk to the surgeons, forget to talk to the house staff or the dentists, you can run into real problems.

Education is a lot of work. In our hospital there's a fair amount of turnover in the support services, so you have to repeat the education process again and again for new personnel. Even when you do this, it seems that no one ever hears you until they've got a problem, and then they'll come back and claim that you never told them in the first place.

Programs need to be aimed at all staff levels and must address the problems and issues important to every-

continued

one—you may need a whole slew of educational efforts. The solution that we and others have come to is that of the multidisciplinary team.

I suspect that everyone who sees a lot of AIDS patients eventually ends up as primary care providers. A team evolves because it is the most efficient way of dealing with multifactorial disease. You need input from the dietitian, the nurses, the social worker; you have to have administrative support in the form of a clinic manager or a secretary to handle the phone calls, arrange the transportation, set up lodging, and so forth. If your staff is making those phone calls, they'll never get anything else done. You have to have some support to facilitate and eliminate those chores so that your health care providers are free to do what they do best.

You must have a dentist. The incidence of periodontal disease in HIV-infected persons is extensive. Patients with wasting syndrome cannot eat if they have rotten, painful teeth. You want to get calories into them, so they've got to see the dentists. They all have skin rashes—obviously all have infectious diseases; they all have neuropathies and dementias; many of them have cancers; and they all have psychological and psychiatric problems.

We started collecting data on the AIDS patients in our hospital in July of 1985. One variable we looked at was length of stay. Our average length of stay is 12.5 days, although we have a large number of very short hospital admissions, often in the clinic or in the intermediate care facility for minor procedures such as rehydration and transfusions.

We also have a number of 21-day lengths of stay at VAMC San Francisco, attributable to the standard 21-day therapy for first-episode *Pneumocystis carinii* pneumonia (PCP). On subsequent episodes of PCP, we will often initiate therapy either in the clinic or after only a few days in the hospital, and then treat these patients at home. The very long stays are generally attributed to those patients who are quite sick, dwindling, or who have serious placement problems because of their diagnosis.

Unlike the situation in New York, we tend to have only six to eight inpatients at any one time. Our intermediate care facility, the Special Diagnostic and Treatment Unit or SDTU, has enabled us to provide an alternative to hospitalization for patients requiring procedures that can get done in one day, and who can be stabilized and then sent home.

In case you think the problem is going away, I want to mention that in October of 1987, we had 25 new patients enter the system. Only four had AIDS; six others suffered from AIDS-related complex (ARC), and 15 were healthy HIV seropositives. This supports the iceberg model of the disease.

There is the real factor of burnout: people who take care of AIDS patients get extremely worn down

I'm particularly excited about three of our protocols. One with the dental service looks at dental concomitant morbidity factors in HIV infection; one includes magnetic resonance spectroscopy and attempts to find a link between HIV dementia and effective intervention with AZT, and the last is our participation in the AZT-ARC cooperative trial.

In conclusion, I'd like to identify some issues not only for us but for the VA as a whole to consider. We must continue to meet the demand for acute care beds and look at ways to decrease lengths of stay, perhaps by utilizing and expanding intermediate or ambulatory facilities. This is clearly the direction the health care industry is taking, and given the economic potential of this epidemic, I believe it's the only way we can afford it.

We have to increase the use of clinical protocols because desperate patients want us to do something, before they turn to the numerous underground drugs that are brought to San Francisco from Mexico and Paris and everywhere else. We must avoid falling into the trap of treating patients empirically, so that we can all learn something about this disease.

We've got to go on addressing issues of staff support, not only in terms of education but also in terms of the very real factor of burnout: people who take care of AIDS patients get extremely worn down. We are in the process of increasing our support network within the hospital at many levels of care, and the response to th efforts is excellent.

Expanding our educational program is an obvious requirement, and establishing liaisons with military programs is also very important. Since the DOD started screening people, patients go in one end of the box, fly out the other, and sometimes land in the VA. We have been working with our colleagues at the Letterman Army and Oakland Naval hospitals in our area to discuss treatment protocols and to collaborate on education programs. The military and the VA are in a unique position to gather epidemiologic data because we can get these patients from the time they're screened, cared for at the military hospitals, and finally enter the VA system. This is a real opportunity to get a handle on the natural history of this disease.

I feel that universal infection control precautions are the only way to go. Whereas that's a lot easier said than done, the method makes sense whether or not you have an HIV problem in your hospital. If the takes the lead in implementing program, it can make a real contribution toward advancing modern infection control concepts.

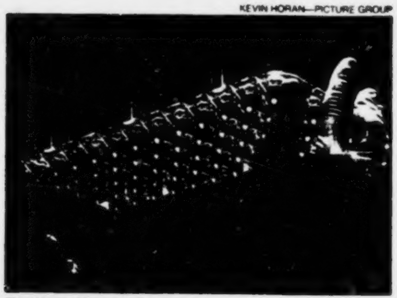
The worsening spread of the AIDS crisis

The panic over AIDS has largely subsided. But the controversies the epidemic has sparked have not gone away. Indeed, the disease's impact is spreading farther and deeper. "There is a dangerous complacency in our country toward an epidemic that many people want to believe is over," the National Commission on AIDS said last month. "Far from over, the epidemic is reaching crisis proportions among the young, the poor, women and many minority communities. It will be much worse in the 1990s than in the 1980s."

The controversies center on how much worse the epidemic will get, whom the virus will strike and, especially, who will pay the massive medical costs. In recent weeks, the government has revised downward its projections of how many people will develop AIDS in the early 1990s and how many are currently infected with HIV. The Centers for Disease Control now estimates that between 246,000 and 298,000 Americans will develop AIDS between now and the end of 1993, down from previous estimates of 295,000 to 325,000. That is in addition to the 115,158 persons diagnosed with the disease as of Nov. 30, 1989. The CDC now puts the number infected at 800,000 to 1.3 million, down from 1 million to 1.5 million. But others have churned the numbers and reached different conclusions. In the most extreme of these projections, questioned by most other experts, the Hudson Institute, a conservative think tank, says there are now 1.9 million to 3 million people infected. In its worst-case scenario, Hudson projects that by 2002 the number of people infected could rise to nearly 15 million if there is no significant medical breakthrough and if behavior changes do not occur. In this gloomy forecast, 2.9 percent of whites, 9.2 percent of Hispanics and a staggering 41.8 percent of blacks between the ages of 15 and 50 could carry the disease. By then, Hudson predicts, at least half of all those infected will be non-drug-using heterosexuals.

A new book, *The Myth of Heterosexual AIDS*, argues the opposite, saying the threat to non-drug-using heterosexuals is extremely small. "Most people have less chance of getting AIDS in the next year than of being struck by lightning or drowning in a bathtub," says author Michael Fumento.

KEVIN HORAN—PICTURE GROUP



Testing time. *Treatment can extend lives*

The reality is no one knows for sure the exact present scope or the future of the epidemic. Large-scale surveys due in two to four years will resolve the issue. In the meantime, most experts say that planning for the worst is the best strategy. "And that is precisely what is not happening," says Dr. June Osborn, chairwoman of the AIDS commission. Hospitals, for example, already overwhelmed in many cities, are in crisis because of the AIDS case load, especially in New York City. AIDS patients fill 1 of every 12 beds in that city at a cost of $1 million a day—a third of which must be absorbed by the hospitals. Similar problems could exist in other cities by the mid-1990s. One suggested solution would create regional hospitals for AIDS care—with separate government funding. Another would expand the amount of home-care assistance available to AIDS patients. Such care is now minimal, and both federal and state agencies have been reluctant to fund it.

Where will the money come from? By most estimates, the costs will stay manageable for the next few years, rising from $4 billion this year to $6 billion in 1993—only a fraction of the total $600 billion health-care tab. But AIDS costs could escalate sharply in the mid-1990s and hit as much as $30 billion a year by the end of the decade. That is more likely if medical treatment continues to extend the lives of AIDS patients and if the legions of the infected who don't have AIDS or any symptoms are successfully treated with drugs that keep the disease at bay.

The cost crunch comes mostly, though, because AIDS is hitting the system at its weakest points. It is increasingly a disease of the poor and disenfranchised. A quarter of AIDS cases now are those who abuse drugs and share needles. In some urban areas, the proportion is 50 percent. And AIDS disproportionately affects blacks and Hispanics, accounting now for 43 percent of all cases. Even in the best of times, these groups are difficult to reach with conventional disease-prevention messages and have less access to private health insurance and medical care.

Fight among the neediest. As costs mount, so could the intensity of the fight among the neediest for government help. In 1989, 25 percent of AIDS medical costs were paid by medicaid, the government health program for the poor; 40 percent of AIDS patients were covered by medicaid, and the proportion is expected to grow. By comparison, medicaid pays 9 percent of all other U.S. health-care costs and pays 40 percent of nursing-home costs for the elderly. Therein lies an awful dilemma. Medicaid is already a target for budget cuts and cannot easily absorb the rising cost of AIDS treatment. Thus, the elderly will increasingly be pitted against AIDS patients for funding.

One proposal would require employers to keep AIDS-disabled workers on company insurance policies until they qualify for medicare, the health program for the elderly and disabled. It will be introduced in Congress soon and could pass. AIDS patients must now wait two years before qualifying, and many do not live that long. A related proposal would eliminate the two-year rule for those without private insurance. But with the medicare budget hemorrhaging, Congress will be reluctant to expand the program.

These controversies are sure to intensify. Despite all that has been learned, the true extent of the AIDS threat remains unknown. Even those on different sides of the issues agree that that should militate against complacency. ■

by Steven Findlay
with Joanne Silberner

How many people have the AIDS virus?

Estimates abound, but no one knows for sure how many people are infected with human immunodeficiency virus (HIV), the cause of AIDS, and how much it will cost to treat them. A clearer picture won't emerge for years, when large population studies are completed.

Number of people with the virus in the U.S. according to—

- **1.9 mil.-3 mil.:** Hudson Institute, a think tank in Indianapolis
- **800,000-1.3 mil.:** Federal government Centers for Disease Control
- **650,000-700,000:** *AIDS Insurance Reports*, an industry newsletter
- **600,000-700,000:** Hoover Institute, a think tank at Stanford University

Projections of the cost of medical treatment in 1991—

- **$15.1 bil. (150,000 cases at $100,580 per case):** Rand Corporation, a think tank in Santa Monica
- **$5.3 bil. (70,000 cases at $75,000 per case):** Federal government National Center for Health Services Research
- **$2.5 bil. (45,000 cases at $53,500 per case):** Hoover Institute

PATIENT EDUCATION FOR HIV PREVENTION

Barbara Hebert Snyder, MPH
May 16, 1989

Purpose of Session

1. Review what we know about changing health behaviors
2. Review elements of effective patient education
3. Apply these findings to AIDS-related behaviors
4. Practice patient education skills

To Change a Health Behavior People Need:

1. Reasons for altering behavior(s)
2. Skills and resources to implement the change
3. Strong belief in their own capability to control their behavior (resilient self-efficacy)
4. Reinforcement and social support for the change

Effective Patient Education Involves:

1. Establishing rapport with the patient
    a. Attending skills
    b. Responding skills
2. Uncovering the patient's concerns/agenda
    a. Patient-centered needs assessment
    b. Personalizing skills
3. Providing information as needed to increase patient awareness of personal risk or correct misinformation
4. Helping the patient initiate a behavioral change

   a. Initiating skills

   b. Negotiating skills

5. Helping the patient develop self-regulatory and social skills to implement desired changes, including

   a. Making choices

   b. Cueing and memory skills

   c. Refusal skills

   d. Managing interpersonal situations/relationships

6. Providing resources (or access to resources) necessary for implementing changes

   a. Specific, concrete information is key to successful referral

7. Enhancing patient's perceived self-efficacy in making the change

   a. Attributing competence to the patient

   b. Modeling, especially using models similar to the patient

   c. Rehearsing difficult social situations

   d. Role playing with corrective feedback

   e. Guiding skill practice until proficiency is achieved

8. Positively reinforcing the patient's attempts; facilitating other social supports to sustain the change

   a. Working with family, significant others

   b. Directing the patient to peer support groups

   c. Supporting renewed effort after perceived failures

Initiating Behavior Change

Facilitating Factors	Hindering Factors

THE HEALTH PROMOTER'S RESPONSIBILITY

To stop HIV transmission, health promoters have a special responsibility to:

Be informed. Information is changing and new discoveries produce new rumors, new fears, new hopes. Health promoters must remain abreast of fresh knowledge, and understand AIDS well enough to describe the current findings to people in ways they can understand and accept.

Be bold. Health promoters must go beyond their accustomed limits to challenge their own assumptions about sexuality, find new resources, and work with people they did not previously believe to be important. No one group alone can stop AIDS.

Be clear. The public must not be misled by ambiguous language, half-truths, or technical jargon. Health promoters must speak plainly, honestly, and directly to people who need to change their present behavior if they are to protect themselves from HIV infection.

Avoid stereotyping and blaming. From the beginning of the HIV pandemic some have sought to blame others, as though some sector of the human race was deliberately spreading HIV. HIV is a virus with no racial, ethnic, or sexual preference.

Concentrate efforts on changing behavior of target groups. General appeals and broad educational approaches can reduce fear and dispel myths, but they have only a minimal effect on behavior. It is not enough to educate the public so that 90% know that AIDS can kill but only 5% of those at risk actually practice safer sex.

Act on a broad front. Even a positive attitude to change is insufficient. The world is full of cigarette smokers who know that cigarette smoking is harmful to their health yet continue smoking. Change in behavior requires a much broader attack; health promoters must understand the reasons people have for maintaining their behavior, find acceptable alternatives, and then provide the resources and support required to introduce the alternatives. Fear alone will not bring about the changes needed to reduce HIV transmission.

SOURCE: "Who AIDS Series 5: Guide To Planning Health Promotion
For AIDS Prevention And Control," World Health
Organization, Geneva 1989

PREVENTIVE MEDICINE 14, 667–669 (1985)

Forum: Patient Education
Introduction

Eight Principles from Patient Education Research

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Patient education is "a planned learning experience using a combination of methods such as teaching, counseling, and behavior modification techniques which influence patients' knowledge and health behavior . . . (and) involves an interactive process which assists patients to participate actively in their health care"(3). Patient education is accomplished by nurses, physicians, dietitians, pharmacists, and others as part of their regular care-giving activities. Patient education can be accomplished on an informal, unplanned basis (and often occurs at the patient's bedside or as part of the office visit) or as part of a systematic protocol. It is this latter form of patient education that receives attention here.

Publication of the seven following articles represents a milestone in patient education research. This collection consists of several reviews of the literature and newly reported empirical findings, and utilizes sophisticated analytical procedures such as meta-analysis and cost-effectiveness analysis. As such, these articles constitute the most comprehensive—and broadest—compilation of patient education research published to date. These papers suggest a host of hypotheses for future research regarding the optimal settings, methods, timing, and content of patient education programs. Just as important, they further solidify the knowledge base for mounting effective patient education programs.

These articles also lend empirical flesh to the bones of what I refer to as the "educational model" of health care, as contrasted to the medical model (1). The educational model focuses on health, not disease; eschews a reductionistic view of illness; assumes that patient and caregiver have approximately equal power; supports an active role for the patient; and accords education a central role in the care process.

The articles are ordered around life stages, beginning with "The Role of Patient Education in the Management of Childhood Asthma" by Sandra Wilson-Pessano and Wylie McNabb (10) and "Improving the Practice of Pediatric Patient Education: A Synthesis and Selective Review" by Philip Nader (8). Patient education for adults is discussed in "Education for Breast Self-Examination: Why, Who, What, and How?" by Steven Kegeles (6), and "Nutrition Education for Risk Factor Reduction and Patient Education: A Review" by Karen Glanz (5). Persons with chronic illness are the subject of "Clinical Trials of Patient Education for Chronic Conditions: A Comparative Meta-analysis of Intervention Types" by Patricia Mullen and colleagues (7), and "Cost-Effectiveness of Educational In-

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terventions to Improve Patient Outcomes in Blood Pressure Control" by Joel Cantor and associates (4). This collection is completed by "Cancer Patient Education: Reality and Potential" by Barbara Rimer and colleagues (9).

These articles represent a distillation of over 450 empirical studies, literature reviews, and other reports previously published in the literature. Given the depth of these papers, it is possible to glean eight fundamental principles to enlighten and guide future patient education research and practice:

(a) Planners of patient education programs need to thoroughly specify the patient behaviors desired and identify the obstacles to performing those behaviors (5, 9, 10).

(b) A combination of educational and behavioral strategies is more effective than one method (9, 10). However, planners must balance effectiveness gains with the increased resource consumption such methods entail (4).

(c) The quality of education may be more important than the educational method used (7). In particular, *individualization* appears to be especially important (5, 7, 9, 10).

(d) Personalized approaches are more effective than mediated approaches (e.g., pamphlets, videotapes) (6, 7), and patient education requires effective interpersonal skills on the part of the caregiver (5, 6).

(e) Knowledge is necessary but generally not sufficient for behavior change (2, 7).

(f) Patient education should be oriented toward what the patient should do, not just what the patient should know. Patient education should include both instructional and behavioral strategies (5, 6, 8–10).

(g) Patient educators need to direct more attention to the long-term performance of desired behaviors (5, 6), enhancing the patient's social support (4–6, 8, 9), and coordinating patient education with community-based health promotion efforts (5, 8).

(h) Patient education programs need to be coordinated with sources of regular medical care (8), although the actual educators do not necessarily need to be direct caregivers (5, 9, 10).

The answers to many research questions remain cloudy, and other questions remain to be formulated. Yet, a considerable body of knowledge now exists upon which effective, practical, and acceptable patient education programs can be developed. More research attention now needs to be directed to the question, Why aren't we applying the knowledge we already have?

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AIDS and Behavioral Change to Reduce Risk: A Review

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Abstract: Published reports describing behavioral changes in response to the threat of AIDS (acquired immunodeficiency syndrome) are reviewed. These studies demonstrate rapid, profound, but expectably incomplete alterations in the behavior of both homosexual/bisexual males and intravenous drug users. This is true in the highest risk metropolitan areas such as New York City and in areas with lower AIDS incidence. Risk reduction is occurring more frequently through the modification of sexual or drug-use behavior than through its elimination. In contrast to aggregate data, longitudinal descriptions of individual behavior demonstrate considerable instability or recidivism. Behavioral change in the potentially vulnerable heterosexual adolescent and young adult populations is less common, as is risk reduction among urban minorities. Reports of AIDS-related knowledge and attitudes generally parallel the pattern of behavioral changes. Nonetheless, few studies investigate the relationship of knowledge and attitudes to risk reduction. Future studies should provide much-needed information about the determinants as well as the magnitude of behavioral changes required to reduce the further spread of AIDS. (*Am J Public Health* 1988; 78(4):394–410.)

Introduction

Since the first cases of acquired immunodeficiency syndrome (AIDS) were identified in 1981,[1,2] biological and epidemiological knowledge concerning the epidemic and the etiology of the syndrome has proliferated rapidly. In particular, the identification of the human immunodeficiency virus (HIV) in 1984 and the development of sensitive and specific anti-HIV antibody tests by 1985 permitted vigorous investigation of transmission and natural history issues.[3] However, the prospect for either a vaccine or a definitive treatment for those already infected remains remote,[4,5] and attention must therefore focus on the only available measure: alteration of those human behaviors essential to transmission of HIV. This was recognized early by gay community groups who issued recommendations for increased care in the selection, and decreased numbers, of sexual partners.[6,7] As additional and more accurate information regarding transmission has become available, the need for behavioral risk reduction has become better specified and more widely discussed. Recommendations have been issued by the Centers for Disease Control (CDC),[8] voluntary organizations such as the American Red Cross, and community groups serving both the gay community and those who use intravenous (IV) drugs.[9]

Briefly, HIV transmission is noted to occur through three mechanisms[10]: both heterosexual and homosexual activity (although the special role of anal intercourse is recognized[11]); direct contact with infectious blood, occurring with the administration of blood products prior to 1985, with intravenous drug use, and by accident; and perinatal transmission from infected mothers to their infants, which may occur either in utero, at birth, or during lactation. Prevention of HIV transmission requires either abstinence from or modification of relevant behaviors. In particular, celibacy and the avoidance of IV drug use would be sufficient to virtually halt the spread of HIV—but widespread compliance with such extreme measures is clearly unlikely,[12,13] necessitating control strategies which involve modification rather than elimination of risk-related behaviors. Thus, "safer sex" guidelines have been developed which urge homosexuals and heterosexuals potentially at risk for transmission of HIV to avoid the exchange of bodily fluids, particularly semen, during sexual activities.[14] The consistent and careful use of well-designed condoms and perhaps a spermicide containing nonoxynol-9 is recommended.[15] For those using intravenous drugs, the sharing of needles and other drug paraphernalia needs to be eliminated, and/or methods for the sterilization of such supplies must be carefully and consistently applied. There are also those who recommend selection of sexual partners based on concordant HIV serologic status[16] (at this point, no data are available concerning this approach, and it remains primarily an intensely debated policy alternative). The discussion which follows will examine selected published evidence concerning the elimination or modification of AIDS-related risk behaviors. Before doing so, however, some attention must be paid to special features of the AIDS threat.

Despite the specific behavioral imperatives posed by AIDS and the more general public health enthusiasm for individual behavioral risk-reduction,[17] idiosyncratic features of HIV infection and AIDS require careful consideration. These features arise from the unique biological characteristics of the retroviruses,[18] from the epidemiologic aspects of the epidemic, and from the enveloping social context. Unlike the preponderance of sexually transmitted diseases, HIV infection and its sequellae are currently incurable, so that persons at risk of infection, or already infected, are asked to undertake lifelong changes in their behavior. In addition, there is little incentive to offer those already seropositive, a circumstance which contrasts sharply with most other risk-reduction recommendations (e.g., in the case of cigarette smoking, those who successfully stop can expect improved respiratory function and reduced risk of heart disease within a comparatively brief period of time).[19,20]

Furthermore, the mechanisms of transmission for HIV call attention to sexual, reproductive, and addictive behaviors, comparatively sensitive and problematic areas for intervention. The development of a public consensus regarding appropriate policies in these areas is elusive, in part due to considerable heterogeneity in underlying social values. Intense debate is common, while coherent intervention/prevention programs are not. Furthermore, these are domains often viewed as more appropriate for private decision-making than for the imposition of public policies. Taken together, these factors suggest that development of AIDS interventions may lag well behind the more biomedical/technological disciplines.

Also, we must obtain and take into account various perspectives of the epidemic from inside the communities at

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risk. Those who are urged to modify their behavior experience the psychosocial burdens of threat, uncertainty, and stigmatization.

- First, the nature and complexity of the threat presented by AIDS is extreme. Not only is survival beyond three years unlikely, but those with the syndrome face the potential burdens of disfigurement from wasting or obvious lesions, disability, dependence, and dementia. Furthermore, this sense of threat extends to one's most intimate relationships; whether or not an infected individual becomes ill him/herself, lovers and children may sicken and die.
- Second, extreme uncertainty characterizes the entire process from exposure through infection to diagnosis, arising from our current lack of clarity concerning the precise circumstances under which infection occurs and progresses. Those at risk often know their potential exposure extends back as long as a decade, so that even comparatively remote behaviors may have resulted in infection. Yet infection is by no means certain even in those who engaged in the highest risk behaviors; the intensity of these behaviors, the seroprevalence of HIV in specific population subgroups, and individual characteristics still largely unspecified may all affect the probability of infection. Even the potentially lethal consequences of infection and their time course remain probabilistic events—increasingly describable in aggregate terms but doing little to reduce an individual's sense of uncertainty. Not surprisingly, available evidence suggests that this uncertainty can result in marked psychological distress.[21]
- Finally, as currently available surveys of both the general public and health care providers suggest, AIDS is a highly stigmatized condition.[22,23] Potential consequences range from disrupted personal or familial relationships through loss of income or insurance benefits to the denial of health care by some providers.

Given these unique features of HIV infection, AIDS, and the social context in which they are occurring, it is unlikely that simple extrapolation from behavioral responses to other chronic or infectious diseases will prove to be helpful, highlighting the importance of accumulated data concerning behaviors specific to AIDS. The review of published reports which follows encompasses two broad issues: behavioral risk reduction, and knowledge/attitudes regarding AIDS. Implications of this review for future practice and research will also be discussed. Our review is not necessarily complete, and is restricted to papers published by mid-1987. The time period in which each investigation was conducted is noted in the accompanying tables.

Behavioral Risk Reduction

This section documents both the extent of behavioral risk reduction and what is known regarding its determinants. Studies reviewed are summarized in more detail in Table 1. Most research to date has been conducted in the male homosexual/bisexual community.

Behavioral Change in Homosexual/Bisexual Men

Findings from these studies will be organized by location. Although rather dissimilar studies are audited, we emphasize a comparative description of three aspects of sexual behavior consistently linked to risk-reduction recommendations: number of sexual partners; frequency of anal intercourse; and use of condoms and/or spermicides.

SAN FRANCISCO

In San Francisco, three separate cohorts are being followed. The San Francisco Men's Health Study provides data on a mixed group of homosexual/bisexual and heterosexual single men recruited by multistage stratified cluster sampling conducted within the 19 census tracks which had experienced the highest cumulative incidence of AIDS through December 1983. The participation rate was 59 per cent. Data from biannual assessments (January 1984 through June 1986)[24] reveal major declines in the prevalence of receptive anal intercourse among seronegative participants, and in the frequency of insertive anal intercourse among seropositives. The prevalence of sexual activity with 10 or more partners during a six-month interval, and insertive and/or receptive anal/genital contact with two or more partners, had declined by at least 60 per cent. No data are provided concerning use of condoms or spermicides. At recruitment, 48.6 per cent of the cohort was seropositive; following the second examination the seroprevalence rate had stabilized at 49.3 per cent, providing evidence of the relation between changes in reports of risk-related behavior and protection from infection with HIV.

In another cohort study, homosexual men were initially recruited in 1983 from four sources: bathhouses; gay bars; advertising for volunteers who had used neither bars nor bathhouses for two months prior to recruitment; and stable "couples" who had taken part in previous investigations. Of those invited to participate, 42 per cent completed and returned the questionnaire (N=655). This recruitment method meant that study participants were more sexually active than those in population-based samples.

Changes in sexual behavior were assessed by asking these men to recall their sexual activity one year earlier, and to concurrently describe their behavior in the autumn of 1983. In their first report, McKusick, Horstman, and Coates[25] indicate that while 35 per cent of the respondents reported a mutually monogamous relationship initially, 41 per cent did so one year later. Receptive anal intercourse without a condom became less common outside of non-monogamous relationships and among those not in relationships. Condom use during receptive anal intercourse increased, yet was reported by only 3.6 per cent to 8.1 per cent of respondents. Although no data are provided, the authors suggest that "selected attitudinal and knowledge items" were related to the number of sexual partners. Men who reported using "hot anonymous" sex to relieve tension or who believed sexual freedom was integral to a gay lifestyle were apparently more likely to have at least three sex partners/month. On the other hand, those who had a "visual image" of AIDS deterioration were more likely to have fewer partners.

A subsequent report from this research group documented changes in behavior observed during a six-month interval following initial assessment:[26] the average number of partners decreased by 13.5 per cent; the 288 respondents who had been in non-monogamous relationships reported that their frequency of anal intercourse without a condom decreased by 46.2 per cent and the average number of their sexual partners per month by 20.4 per cent. Several other measures of sexual behavior show changes in the direction of reduced risk-related activities: a 28.6 per cent decline in number of anonymous sexual partners, a 50 per cent decline in oral-anal contact, a 27.3 per cent decline in proportion swallowing semen, and, even more dramatically, a 60 per cent decline in average number of visits to a sex club or

TABLE 1—Published Studies of AIDS-Related Behavioral Risk Reduction

	Sample		Study			Results		
Author	Description	Sociodemographics	Design	Sampling	Assessment	Behavioral Change	Validation of Change	Determinants of Change
Winkelstein et al[24]	San Francisco: 641 homosexual 171 bisexual men	25–54 years old 43.3% exec, prof 89.8% 2 yr college	Longitudinal: 1984–86	Area-specific probability sampling (59% participation)	Structured interview & biomed evaluation 4 biannual assessments	Prevalence of ≥10 sex partners/6 mos declined 60% or more among seronegatives: RAI* 14% at entry 5.9% at Time 2 4.9% at Time 3 5.8% at Time 4 among seropositives: IAI† 39.6% at entry 25.6% at Time 2 16.8% at Time 3 13.8% at Time 4 condom use not reported	HIV seroprevalence 48.6% at entry 49.6% at Time 2 then stable	Not reported
McKusick et al[25]	San Francisco: 655 homosexual men	Specific to each subsample $\bar{x}$ age 30.5–33 61%–81% prof or white collar 86%–94% White 5%–44% in committed monog relat	Cross-sectional survey (1983) with retrosp comparison to 1 yr earlier	4 sources: bathhouses (N = 151) bars (N = 134) no bathhouse/bar (N = 181) couples (N = 186) 42% particip	Self-admin quex	Monogamy 35% 1 yr earlier 41% 1983 RAI without condom ≥1 times/mo among monogamous men (N = 159) 60.0% 1 yr earlier 59.1% 1983 RAI without condom ≥1 times/mo among men in nonmonog relat outside the relat 40.0% 1 yr earlier 30.2% in 1983	Not reported	Assoc with more partners: use of sex to relieve tension, perceiving sexual freedom as gay lifestyle, assoc with fewer partners: recall seeing victim with advanced AIDS
McKusick et al[26]	San Francisco: homosexual men 655 (x-sect), 454 (longit)	Not reported	Retrosp: 1982; longitudinal 1983–1984	As above	Self-admin quex	$\bar{x}$ # sex partners/mo 3.7 in 1982 3.2 in 1983 among 288 in non-monog relat: AI‡ without condom/mo 1.9 in 1982 1.3 in 1983 0.7 in 1984 among 255 in primary relat: AI without condom/mo 3.3 in 1982 2.5 in 1983 2.3 in 1984 condom use in primary relationships not increased	Not reported	(criterion p = .10) *Maintaining* 0–2 partners/mo: first homosex experience ≥18 years ago *Reducing* # partners/mo: visual image of AIDS deterioration younger (age ≤40) first homosex experience ≤26 years ago
Stall et al[27]	San Francisco: 464 homosexual non-monog men (subsample of McKusick cohort)	Not reported	Cross-sectional survey (1985) retrosp analysis (1984)	As above	Self-admin quex	Multi-item risk index among "no risk" 1984 (N = 100): 46% "no risk" 1985 54% "more risk" 1985 among "high risk" 1984 (N = 211): 45% "less risk" 1985 55% "high risk" 1985	Not reported	Increased risk assoc with: alcohol, drug use during sex; number of substances used; frequency of alcohol use

	500(x-sect), 301 (longit)			(81.4% participation)		36% 1985 AI without condom with non-primary partner past 30 days 18% 1984 12% 1985		
Martin[29]	New York City: 745 homosexual men	x̄ age = 35.7 x̄ yrs educ = 16.3 87% White 37% had current "lovers"	Cross-sectional survey (1985) retrosp comparison to "pre-AIDS"	Convenience	Interviewer admin quex	"Extra-domestic" sex: median # sex partners/year: pre-AIDS = 36 1985 = 8 "domestic" sex: median # sex partners/year: pre-AIDS = 5 1985 = 3 IAI and RAI median freq "declined by over 75%" pre-AIDS to 1985 condom use during: IAI 10% pre-AIDS 20% 1985 RAI 2% pre-AIDS 19% 1985	Not reported	Not Reported
Martin[30]	New York City: 745 homosexual men	Same as above	Same as above	Same as above	Same as above	Multi-item risk index multiple partners & higher risk activity 81% pre-AIDS 60% 1985 multiple partners & lower risk activity 9% pre-AIDS 23% 1985 monog & higher risk activity 6% pre-AIDS 8% 1985 monog & lower risk activity 2% pre-AIDS 7% 1985 celibate 2.5% pre-AIDS 3.5% 1985	Not reported	Not reported
Emmons et al.[31]	Chicago: 978 homosexual/ bisexual men	x̄ age = 34.6 x̄ educ = 16 yrs primary relat = 49.5%	Cross-sectional 1984–1985	Convenience	Self-admin quex	76.5% attempt to reduce part # 12.9% avoid RAI 20.2% practicing RAI avoid semen contact by condoms, withdrawal	Not reported	Health Belief Model assessed in relation to 5 outcomes knowledge consistently important and perceived efficacy, perceived risk, belief in biomedical technology, social norms, all occasionally import
Joseph et al.[32]	Chicago: 637 homosexual/ bisexual men	x̄ age = 35.2 x̄ educ = 16.3 yrs 92% White	Longitudinal: 6 mos 1984–85	Convenience	Self-admin quex	x # sexual part/mo decreased 1.74 monogamy 17.6% at baseline 24.6% 6 mo later RAI 54.1% at baseline 48.6% 6 mo later condom use during RAI 16.5% at baseline 26.7% 6 mo later	Not reported	Health Belief Model assessed in relation to 7 outcomes knowledge not predictive of longitudinal change social norms only consistent predictor of change

(continued next page)

TABLE 1—Continued

	Sample		Study			Results		
Author	Description	Sociodemographics	Design	Sampling	Assessment	Behavioral Change	Validation of Change	Determinants of Change
Golubjatnikov et al[33]	Madison, WI: 488 homosexual men	Not reported	Surveillance 1982–83	Convenience: STD clinic patients	Not reported	$\bar{x}$ # sex part past mo: 6.8 1982 3.2 1983	Not reported	Not reported
Burton et al[34]	UK, Central London: 326 homosexual men	Not reported	Survey 1986	Convenience from pubs and clubs	Interview	Decreased # sexual part/mo in comparison to previous year: 48% condom use during AI: 49% condom use during AI among those with multiple sex partners: 59%	Not reported	95% report receiving safe sex information 75% "welcomed and followed" safer sex guidelines
Carne et al[35]	UK, Middlesex: 100 homosexual men	Not reported	Longitudinal "at least one year" 1984/1985–86	Convenience	MD or RN-admin quex	Median # sex part/mo: 3 in 1984/1985 1 in 1986 IAI with ≥2 part/mo: 27% in 1984/1985 8% in 1986 RAI with ≥2 part/mo: 41% in 1984/1985 16% in 1986	Not reported	Not reported
Anderson et al[36]	UK, Paddington all population groups	Not reported	Intervention: UK public media campaign (1986) evaluation: frequency of requests for HIV serologic testing pre/post no controls	Population-based surveillance	Change in frequency of requests for HIV serologic testing	Increase in frequency of test requests in media campaign week: 191% among homosexual men 138% all others	Not reported	Intervention campaign
Friedman[40]	New York City: 59 clients in methadone maintenance programs	Not reported	Cross-sectional survey 1984	Convenience	Interview	Behavioral change to reduce AIDS risk: 59% increased use of clean/new needles: 31% reduced needle-sharing: 29%	Not reported	Not reported
DesJarlis[41]	New York City: 22 IV needle sellers on streets	Not reported	Street ethnography 1985	Convenience	Interview	18/22 report new needle sales increased; 4/18 cite AIDS as cause of demand for new needles 10/21 report selling old needles as new	Not reported	Not reported
Chaisson[43]	San Francisco: 152 IVDU (1985) 172 IVDU (1987) volunteers from drug treatment center	Not reported but "similar" in 1985, 1987	Intervention 1986: community health outreach to IVDUs, distribution of 5.25% sodium hypochlorite invails; media campaign evaluation pre (1985) post (1987) no controls	Convenience	Not reported	Needle-sharing 71% in 1985 71% in 1987 use of bleach solution to clean needles, if sharing 6% in 1985 47% in 1987	Not reported	Not reported

Marks & Parry[44]	UK: Liverpool IVDUs	Not reported	Intervention: program for needle/syringe exchange of sterile equipment for used (Nov 1986–Jan 1987) evaluation: utilization of program no pre/post no controls	Not applicable	Utilization of needle/syringe exchange	3,237 needles/syringes distributed in 3 mos. 2,949 returned and exchanged 1.75 registered IVDUs to 1.0 unregistered	Not reported	Not reported
Agle et al.[50]	Multi-center, USA: hemophiliacs N = 116 spouses N = 40 parents N = 94	$\bar{x}$ age pts. = 29	Cross-sectional survey 1983–1984	Consecutive unselected patients at treatment centers	Self-admin quex	Decreased frequency of intercourse due to AIDS 10.8% spouses 8.1% hemophiliacs	Not reported	Not reported
Winkelstein et al.[51]	San Francisco: 123 heterosexual men	25–54 years old	Longitudinal: 1984–1986	Area-specific probability sampling	Structured interview + biomed evaluation 4 biannual assessments	Mean # female sex part/6 mo 2.81 at entry 1.81 at Time 4 condom use not reported	Not reported	Not reported
Padian et al.[52]	San Francisco 97 heterosexual female partners of men infected with HIV	age 19–65 yrs 92% White 57% part of bisexual men	Longitudinal, recruitment began 1985	Special recruitment	Interview and biomed assessment	Evidence of change to "safer sex" practices among 1/3 of seronegative women	Prevalent serologic data only	Not reported
Strunin & Hingson[53]	Massachusetts: 829 adolescents 16–19 yrs old	Not reported	Cross-sectional survey 1986	Random digit dialing (86% participation)	Telephone interview, anonymous	Risk behavior prevalence 1% IVDUs 55% report sexual intercourse of whom 98% heterosex, 0.7% homosexual male, 0.5% bisexual change in sexual behavior due to AIDS: 15%, of these: 10% use condoms 10% celibate 35% more selective partners 25% "careful" change in IVDU behavior 1/3 (N = 3) stopped needle use 1/3 (N = 3) stopped IVDU 1/9 (N = 1) using clean needles 2/9 (N = 2) use less drugs/no longer use "AIDS drugs"	Not reported	Not reported
Simkins & Kushner[55]	Kansas City: 212 college students, heterosexual & homosexual	$\bar{x}$ age = 22 yrs 42% male 84% single 77.4% heterosex 50% with current sex partner	Cross-sectional 1985 survey, comparison to similar 1984 survey in same pop	Convenience: psychology classes + special recruitment of homosexual men and women	Self-admin quex	AIDS does *not* influence sexual behavior = 68.4%	Not reported	Correlation between sexual activity and AIDS concern = −.049 (not signif)
DesJarlais et al.[56]	New York City: 67 jailed female prostitutes	Not reported	Cross-sectional 1986	Convenience, and key informants	Not reported, key informants interviewed	92% required customers to use condoms	Not reported	Key informants indicate use of condoms began in 1970s in response to concerns re: herpes, STDs

‡AI = anal intercourse
†IAI = insertive anal intercourse
*RAI = receptive anal intercourse

TABLE 2—Published Studies of Knowledge and Attitudes Relevant to AIDS

	Sample		Study			Results			
Author	Description	Sociodemographics	Design	Sampling Method	Assessment Method	Knowledge of Transmission	Knowledge of Prevention	Perception of Risk	Other
McKusick et al[28]	San Francisco: homosexual/bisexual 655 (x-sect) 454 (longit)	Not reported	Retrospect: 1982 longitudinal 1983–1984	4 sources: bathhouses (N = 151) bars (N = 134) no bathhouse/bar (N = 181) couples (N = 186) 42% particip	Self-admin quex	Agreement with risk reduction guidelines: high = 52.6%		Friend with AIDS: 17.9% Visual image of AIDS: 64.9%	
Joseph et al[32]	Chicago: 637 homosexual/bisexual men	$\bar{x}$ age = 35.2 $\bar{x}$ educ = 16.3 yrs 92% White	Longitudinal 6 mos 1984–1985	Convenience	Self-admin quex	Combined knowledge $\bar{x}$ score: 71.4% Belief in vaccine or cure $\bar{x}$ score: 40.0%		Perceived AIDS risk $\bar{x}$ score: 44.4%	Social norms supportive of safer sex $\bar{x}$ score: 64.0% (strongest predictor of longitudinal risk reduction)
Valdiserri et al[61]	Pittsburgh: 464 homosexual/bisexual men	$\bar{x}$ age = 33 66% college grad	Intervention: one 60 min group of 5–10 participants; knowledge focus Evaluation: pre/post no controls	Prerequisite for HIV test disclosure (32% participation)	Self-admin quex pre and 1–2 weeks post	Transmission of HIV: 86% × correct pre 94% × correct post	Not reported (see attitude results)	Perceived vulnerability 67% pre 72% post	Attitude change: number part/anomy partners 71% pre 72% post endorse condom use 65% pre 73% post discuss AIDS prevt with partners 48% pre 56% post
Williams[63]	Detroit: 62 homosexual men	All Black	Survey 1985	Convenience	Administered quex	Transmission via blood and semen: 13% correct	Not reported	Worry about AIDS infection: 37% not worried 19% very worried	
Friedman et al[40]	New York City: 59 clients in methadone maintenance program	Not reported	Survey 1984	Convenience	Interview	93% knew IVDU can transmit 88% knew ≥2 modes of transmission	Not reported	Not reported	Not reported
	146 methadone maintenance clients & 115 incarcerated drug users	Not reported	Not reported	Not reported	Interview	97% knew IV needle use can transmit >50% believed shared utensils can transmit	Not reported	Not reported	Not reported
Ginzburg et al[45]	New Jersey: 175 IVDUs in drug treatment program	57% men 58 White 34% Black median age = 32 yrs 60% HS grad or equivalent	Survey 1984	Not reported	Administered quex	95% knew IVDUs high risk group 95% knew transmission in IVDUs due to needle-sharing	Not reported	Not reported	Not reported
	577 IVDUs entering drug treatment programs	70% men 50% White 30% Black median age = 32.5 yrs	Survey 1985	Not reported, but "representative" of all admissions re: age, gender, race, and ethnicity	Administered quex	"Continued awareness" of transmission (NFS)" 57% knew infants of	29.3% knew dilute bleach would inactive HIV	Not reported	Source of information: 78% TV 57% radio 15.3% field worker

Williams[63]	Detroit: 98 methadone maintenance clients	Not reported	Survey 1985	Convenience	Administered quex	82% knew IVDUs high risk group	87% knew avoidance of IV drugs would prevent infection 68% knew not sharing needles would prevent infection	Concern/worry about getting AIDS: 57% unconcerned 11.2% very worried	Sources of ~50% unaware of source for AIDS information
Price et al.[64]	Ohio: 250 high school students	47.2% men age 16–19 years	Survey 1984	Convenience	Classroom quex	In best informed students, only 47% correct responses (NFS)	Not reported	Worry about getting AIDS: 73% not worried	Most information from mass media
DiClemente et al.[65]	San Francisco: 1326 high school students	age 14–18 years "all major ethnic groups represented"	Survey 1985	Inclusive: all students at selected high schools (99% participation)	Self-administered classroom quex	92% knew sex could transmit	60% knew condoms could help prevent infection	79% "afraid" 74% "worried"	88% believe school curriculum on AIDS important
Strunin and Hingson[53]	Massachusetts: 829 adolescents	Not reported	Survey 1986	Random digit dialing	Anonymous telephone interview	91% knew heterosexuals at risk 71% knew HIV in vaginal secretions	Not reported	54% not worried at all about getting AIDS 61% thought not at all likely to get AIDS in their lifetime	97% believe AIDS information should be available at school
Simkins and Kushner[55]	Kansas City: 212 college students	47.2% male 77.4% heterosexual 10.8% homosexual 3.3% bisexual 6.1% celibate	Survey 1986	Convenience	Classroom quex	Not reported	Not reported	Concern equal re: AIDS and herpes risk 71% no concern about getting AIDS from present partner	Homophobia scale significantly correlated with AIDS concern; males more homophobic than females
Sherr et al.[66]	UK: London: higher risk = STD clinid pts N = 156 pre 105 post #1 145 post #2 lower risk = law students or general practice pts N = 83 pre 75 post #1 134 post #2	Not reported	Intervention: 2 public media campaigns Evaluation: pre/post no controls	Convenience	Not reported	"Information levels were significantly raised by the first ($p = .03$) and second ($p < .001$) campaigns" (NFS)		Not reported	
Hastings et al.[67]	UK: Glasgow & Edinburgh 84 general population	Age 20–50 50% male	Focus group discussion of AIDS and proposed health education brochure 1986	Selected to be representative of population	Group discussion, qualitative data only	Knowledge "generally superficial and vague" (NFS) generally seen as transmitted through sex or blood most believed social contact could transmit		Not reported	Attitudes toward high-risk individuals "profoundly negative" (NFS)

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*NFS = not further specified

bathhouse for sex. Among those in a primary relationship, there was a significant decrease in average number of sexual encounters/month, from 9.7 to 8.5.

In addition to these aggregate data, of those who initially had two partners per month or less, 70 per cent maintained this level of sexual activity, while among those who had three or more partners initially 41 per cent reduced their number of sexual partners to less than three.

Somewhat contradictory findings regarding the predictors of two behavioral patterns were reported. Those who initially had 0–2 partners/month were more likely to maintain this lower risk level if they had become homosexually active at least 18 years ago. On the other hand, those who successfully reduced their number of sexual partners during the follow-up period were more likely to have become sexually active in the past 26 years, to be 40 years old or less, and to have a visual image of AIDS deterioration. Relationship status, agreement with AIDS risk-reduction guidelines, and knowing a friend who has AIDS or has died from it were not related to either positive behavioral outcome.

A later report of sexual behavior in the same cohort[27] which employed a summary risk measure was confined to the 463 individuals not in a monogomous primary relationship at the time of the second assessment (1985), a selected subsample for whom behavioral risk reduction may be most salient. Sexual behavior was scored as "completely safe" (e.g., massage), "probably safe" (e.g., anal intercourse with condoms), "probably risky" (e.g., ingesting semen during oral-genital sex), or "risky" (e.g., anal intercourse without a condom): 25.3 per cent of the men were at no risk; 36.9 per cent at medium risk; and 37.8 per cent at high risk. The same score was then calculated at the prior assessment one year earlier. Cross-sectional analyses of 1985 data demonstrated that both alcohol and drug use of all kinds were significantly associated with an increased level of risk.

Retrospective analyses compared those originally at no risk with those originally at high risk. During the subsequent year, 54 per cent of those originally at no risk engaged in behaviors which placed them at greater risk, while 45 per cent of those originally at high risk were subsequently engaging in safer behavior. Those who increased their risk were more likely to subsequently report use of drugs and alcohol during sex. Since it was substance use during the second observational period which was correlated with change in the preceding year, this analysis leaves unexamined the issue of causality. The direction and magnitude of the relationship between substance use and unsafe sexuality, as well as their relationship to other potentially causal variables (such as personality predispositions), require further exploration.

A third study conducted in San Francisco randomly sampled telephone numbers listed with only a male name.[28] Men who identified themselves as "gay or bisexual" were eligible for interview and, of these, 81.4 per cent participated. Telephone interviews were conducted with 500 men identified in this fashion in 1984, and nine months later a random subsample of 301 was re-interviewed (93.2 per cent participated). The number of respondents reporting sex with more than one partner in the past month declined by 27 per cent, while the proportion reporting celibacy, monogamy, or no sex leading to exchange of semen outside a "primary relationship" rose from 69 per cent to 81 per cent, and anal intercourse without a condom, conducted outside a primary relationship, decreased from 17 per cent to only 7 per cent.

NEW YORK CITY

Martin has reported on sexual behavior in a well-educated convenience sample of 745 self-identified gay men aged 20–65.[29] An interview format was used which allows comparisons between recent behavior during an entire year and that recalled for a year prior to hearing about AIDS. For those men who reported sexual activity at locations other than home, the median number of sexual partners per year declined from 36 pre-AIDS to eight post-AIDS. All but one of the men in the cohort reported sexual activity at home; the median number of sexual partners in this location declined from five to three during the same interval. The number of reported receptive anal sex episodes declined by 75 per cent; use of condoms by the respondent's partner during episodes of receptive anal intercourse increased from 2 per cent to 19 per cent of the episodes.

In another report,[30] Martin combined these data to describe seven distinct risk categories. The most extreme typology was limited to men who had multiple partners (whether at home or elsewhere) and had engaged in high-risk acts. Between the time periods being compared, there was a 26 per cent reduction in the prevalence of this behavioral pattern, while all other patterns became more common. The least change was observed in those choosing to remain celibate (+1 per cent). Restricting sexual activity to lower risk behavior and eliminating sex outside the home were the most frequently changed aspects of behavior. In summary, 40 per cent of the sample decreased their level of risk between the two time periods, 49 per cent did not change, and 8.3 per cent increased their risk. This approach understates changes in behavior since a man who decreased the number of his sexual partners from 20 to two remains classified as having multiple sexual partners in spite of marked change.

OTHER US STUDIES

A cohort of approximately 1,000 homosexual/bisexual men living in Chicago, a less heavily affected area, are participants in an HIV natural history study and receive biannual medical and laboratory examinations, as well as providing extensive behavioral and psychosocial data in a concurrent study. This group of recruited volunteers closely resembles the men being studied both in San Francisco and in New York City. Cross-sectional analyses were confined to the 909 men not diagnosed with AIDS, not being paid for sex, and for whom data were missing on no more than three variables;[31] in 1984–85, 80.5 per cent reported making at least some behavior changes because of AIDS, and 76.5 per cent had specifically attempted to reduce their number of sexual partners. Of the 486 men continuing to engage in receptive anal intercourse 20.2 per cent were modifying this behavior by asking their partners to use a condom or to withdraw prior to ejaculation.

Multivariate analyses described the comparative contribution of components of the Health Belief Model (HBM) to five self-reported changes: any behavioral change because of AIDS; attempts to reduce the number of sexual partners; avoidance of anonymous sexual partners; avoidance of receptive anal sex; and modification of receptive anal sex. Knowledge regarding AIDS, and the perceived value of behavioral change in reducing one's risk of AIDS, were both consistently related to various measures of risk reduction. In addition, supportive peer norms, reliance on biomedical technology to prevent/cure AIDS, difficulties with sexual impulse control, and perceived risk of AIDS were all related to at least one of the outcome measures; however, the effects of perceived risk were inconsistent. The cross-sectional nature of these analyses leads to cautions concerning presumed causality.

Subsequent longitudinal analyses by Joseph and others describe changes in the 637 men from the cohort for whom data were available both at entry into the study and six months later.[32] Sociodemographic characteristics remained largely unchanged in this subsample. There were reductions in the mean number of sexual partners per month, in the number of receptive anal exposures, in the number of anonymous partners, and in the number of total oral and/or anal exposures. By the second assessment, 51.4 per cent of the cohort was no longer engaging in receptive anal intercourse, and among those doing so there was an increase of 61.8 per cent in the use of condoms or withdrawal to prevent exposure to semen.

The HBM was again examined for its relationship to longitudinal change after taking account of baseline behavior—an important step because one of the strongest predictors of future behavior is past behavior. Generally diminished associations were observed: for example, knowledge was unrelated to any of the seven behavioral outcomes examined in the longitudinal analysis. Supportive social norms provided the only exception to this general trend of diminished effects in longitudinal analyses, being consistently and positively related to a range of risk-reduction behaviors. The authors concluded that, to some extent, there may be differences between factors that predict the initiation of behavior and those which predict its subsequent maintenance and/or incremental improvement.

A brief report from Wisconsin documents changes in number of sexual partners among 488 homosexual men seen at a clinic for the treatment of sexually transmitted diseases or screened for such conditions in gay bars.[33] Approximately twice as many men reported a single sexual partner and an increase in celibacy was observed when during the same six-month period in 1983 was compared with a year earlier. There was also a "sharp decline" in the proportion of men reporting 10 or more sexual partners.

STUDIES IN THE UNITED KINGDOM

A survey was undertaken in central London of 326 gay men in pubs and clubs in order to assess the affects of the AIDS epidemic and of "safer sex" publicity on behavior.[34] Of those interviewed, 95 per cent had received information on "safer sex," and 77 per cent said that AIDS had changed their sex life. Although 53 per cent of the men were continuing to engage in anal intercourse, 45 per cent of these were using condoms (59 per cent of those with multiple sexual partners), and 48 per cent of the respondents reported fewer sexual partners this year than in the previous year.

Carne, *et al*,[35] documented changes in sexual behavior among the first 100 members of a larger cohort of homosexual/bisexual men originally recruited in late 1982 in London. Between 1984–85 and 1986, median number of sexual partners/month declined from three to one; there was a 70 per cent decline in prevalence of anal intercourse with two or more partners in a typical month; and there was approximately a doubling of condom usage among those reporting receptive and insertive anal sex.

In the UK, mass media publicity campaigns are reported to have resulted in a 191 per cent increase in the number of homosexual/bisexual men seeking AIDS testing, a 73 per cent increase by those using intravenous drugs, and a 57 per cent increase among those who described themselves as prostitutes.[36]

Behavioral Change in Intravenous Drug Users

Intravenous drugs users (IVDUs) are the second largest AIDS risk group.[37] Prevention of transmission among IVDUs requires that they either abstain from drug use or modify their drug use behavior. Effective safety precautions consist of not sharing needles and syringes, or adequately sterilizing them between use (it has been demonstrated that a 10 per cent solution of household bleach and water is sufficient to inactivate HIV).[38] Infected intravenous drug users also may transmit infection to their heterosexual partners and children. Routine "safer sex" practices including condom and spermicide use are recommended for this population.

Unlike the gay community, which is relatively organized and generally characterized by educational and socioeconomic advantage, more IVDUs are members of minority communities and their average level of education is lower.[39] Language and literacy problems are well recognized, and communication in this subculture is generally oral rather than written. Furthermore, both the majority culture and the IVDU subculture tend to hold negative stereotypes of one another. There is a general impression that IVDUs are incapable of (or disinterested in) changing their behavior, while IVDUs view public health authorities with suspicion and distrust. In this context, it is particularly important to base interventions upon empirical findings.

Data from New York City provided by Friedman and others suggest that, as early as 1984, there were already AIDS-related behavioral changes among some groups of IVDUs[40] Interviews were conducted with 59 patients in Manhattan methadone maintenance treatment programs; the majority (59 per cent) reported behavioral changes to avoid AIDS: increased use of clean needles and/or the cleaning of their needles (31 per cent), and reduced needle-sharing (29 per cent); 51 per cent reported that their friends had also changed their behavior. Level of education (although not further described) was reportedly unrelated to extent of behavioral change.

Friedman also describes work by Selwyn and others conducted in New York City among 145 methadone maintenance patients and 115 incarcerated drug users. They found that over 60 per cent of their respondents reported making one of the following changes in order to avoid AIDS: no longer sharing needles although continuing IV drug use; decreased needle sharing; stopping IV drug use completely; or attempting to sterilize their needles. He also found that 48 per cent had decreased their number of sex partners, were using condoms, or were taking other "hygienic" measures in order to practice safer sex.

This report also provides brief ethnographic data suggesting that the illicit market in New York City for sterile needles has increased considerably, and that drug dealers have begun distributing "free" sterile needles or syringes since the beginning of the AIDS epidemic. Unfortunately, Friedman also reports that some are fraudulently selling used needles as new.

Des Jarlais, *et al*,[41] interviewed IVDUs who are not in any form of drug abuse or health care treatment—respondents potentially more representative of those at greatest risk. Interviews were conducted through an ethnographic storefront center and the Street Research Unit.[42] As early as fall 1983 intensive interviews with 18 IVDUs at the storefront suggested an increased demand for new needles as a result of

AIDS. During the spring of 1985, brief street interviews were held with 22 needle sellers, 18 of whom reported that new needle sales had increased over the last year. However, only four of these specifically mentioned AIDS as a reason for the increased demand. It should be added that 10 of these sellers reported that they had sold used needles as new at some time, and seven stated that they had resealed used needles in order to do so.

In San Francisco, in July 1986, public service agencies began training community health outreach workers to IVDUs not in treatment regarding AIDS and appropriate behavioral risk reduction.[43] More than 15,000 vials of a 2.5 per cent bleach solution were distributed to addicts, accompanied by instructions on their use for sterilization of drug equipment. Posters and billboards were used also to promote the use of bleach in the prevention of HIV transmission. In 1985, only 6 per cent of those who shared needles reported that they usually or always sterilized them with bleach; in the 1987 sample, this figure had risen to 47 per cent. The proportion reporting that they never used bleach fell from 76 per cent to 36 per cent in the same two groups. Interestingly, a consistent 23 per cent reported that they usually or always sterilized their equipment with alcohol. During the same period the prevalence of HIV antibodies among IVDUs in treatment increased from 10 per cent to 15 per cent, suggesting that other measures, particularly the provision of sterile hypodermic needles, need to be undertaken in these populations.

A report of exactly such a program is available from Liverpool where, since 1986, the municipal drug dependency clinic has been providing drug users with sterile needles and syringes in exchange for previously used ones.[44] In the initial months of the program, 3,237 syringes and needles had been issued and 2,949 had been returned. The ratio of those in treatment to those not in treatment using the facility is 1.75 to 1. Those who attend are encouraged to use condoms, which are supplied free on an experimental basis by a manufacturer (no data are available concerning the utilization of these condoms).

These quantitative assessments of risk reduction among IVDUs are supported by a more qualitative description derived from a study by Ginzberg, *et al.*[45] They also noted an increased demand for sterile syringes, both in New York City and in northern New Jersey.

Risk Reduction Behavior in Other Groups

In this portion of the review, we will discuss studies of behavioral risk reduction in heterosexuals who are not IVDUs.[46,47]

Sexual transmission of HIV from hemophiliacs to their sexual partners and children is well documented,[48] and the National Hemophilia Foundation has acted to provide information and guidelines for behavioral risk reduction.[49] However, the limited number of published reports focus on psychosocial or psychological consequences of being at risk, rather than on behavior. Minimal data are provided by Agle and others who conducted a multicenter study of 116 hemophiliacs, their parents, and their partners.[50] The report primarily documents affective or attitudinal changes, and the differences between the three groups studied. Nonetheless, there was evidence of a decreased willingness to receive factor concentrate because of AIDS, and both hemophiliacs and their partners reported decreased sexual desire and frequency of sexual behavior because of their concerns about AIDS. Obviously, decreased frequency of intercourse is not an appropriate method for behavioral risk reduction; no data are provided concerning condom or spermicide usage.

Using the same methods for recruitment and study as were applied to homosexual/bisexual men,[24] the San Francisco Men's Health Study documented the behavior of 123 single heterosexual men.[51] Heterosexual participants had fewer sexual partners than homosexual/bisexual men living in the same area, and had also substantially reduced their number of sexual partners.

In a later report from San Francisco, Padian and others describe the serologic status and behavior of 97 female partners of 93 men known to be infected with HIV or diagnosed as having AIDS or ARC.[52] Women who used intravenous drugs or who had recently received blood transfusions were eliminated from all analyses. Most of those recruited were the partners of bisexual men (57 per cent), while others were the partners of hemophiliacs (19.6 per cent), of intravenous drug users (12.4 per cent), or of those who had received transfusions or who were both bisexual and IVDUs. This report is primarily concerned with the natural history of HIV transmission and infection in this group of women. Although precise figures are not provided, the authors state that one-third of the seronegative women and all seropositive women reported changing to safer sexual practices (in particular, condom use) after hearing about AIDS. This provides some evidence of behavioral risk reduction occurring among heterosexual women at greatest risk for infection with HIV.

Several reports have documented risk-related behaviors and changes in such behaviors among adolescents and young adults. In one investigation, 963 Massachusetts teenagers were contacted by random-digit dialing;[53] 829 (86 per cent) agreed to participate in the survey. Knowledge concerning AIDS was incomplete at best. In this sample, there were few IVDU and male homosexual contacts. Among sexually active respondents, only 15 per cent indicated changes in their sexual behavior because of concern about AIDS; 35 per cent said they were more selective in their choice of partners, and another 25 per cent that they were "careful". Only 10 per cent reported using condoms, with another 10 per cent stating that they now abstained from sex.

Research work conducted in Kansas City among volunteers from psychology classes, from the gay and lesbian student service, and from gay bars provides limited behavioral data. These similar studies appeared in 1984[54] and 1986,[55] and the sociodemographic characteristics of participants are virtually identical. There were a few more men than women; approximately three-fourths were single; three-fourths were heterosexual (the remainder being identified as homosexual, bisexual, or celibate); slightly over half currently had sexual partners; and the average age was approximately 22. There was little change in behavior noted between the two surveys, with only one-fourth stating that fears regarding AIDS had affected their sexual behavior (an equal proportion reported that herpes had had the same effect).

It is generally recognized that heterosexual contact with prostitutes may constitute an especially risky behavior, both because of the large number of sexual partners inherent in prostitution, and because IVDU is common in this group. It then becomes particularly important to document preventive behaviors in prostitutes and their clients. Des Jarlais and others[56] present data from 67 jailed "street" prostitutes, among whom 92 per cent reported that they "usually required" clients to use condoms. Additionally, oral-genital sex was the predominant sexual activity, further reducing the likelihood of HIV transmission. However, key informants reported that these behaviors were adopted in the early 1970s in response to general concerns about sexually transmitted diseases rather than as a consequence of the AIDS threat.

Studies of AIDS Knowledge and Attitudes

Although it is obvious that the prevention of HIV transmission is dependent upon the alteration of behavior, most would agree that appropriate knowledge and attitudes are prerequisites for such change.[57,58] Although a wide variety of specific topics are documented in various reports, this review will concentrate on three central questions: how adequate is knowledge regarding the mechanism of HIV transmission? how adequate is knowledge regarding preventive methods, especially those particularly relevant to the sample being studied? to what extent is there a sense of personal vulnerability or risk which would make the available knowledge concerning transmission and prevention salient? In addition, we are concerned with the prevalence of misinformation or inaccuracies in preventive knowledge. This is important because it may be that, while individuals can correctly identify several mechanisms for transmission, this is only because they affirm that *all* modes of transmission are possible. Such a response set would suggest a generalized sense of hazard due to HIV, rather than an appropriate focus on specific mechanisms of transmission and their prevention.

Studies of Homosexual/Bisexual Men

McKusick and others assessed variables which could be construed as broadly describing both knowledge and perceived risk.[26] Of the 424 sample participants, 52.6 per cent expressed a "high" level of agreement with the guidelines for behavioral risk reduction. Seemingly, this would require both an adequate level of knowledge about, and appropriate attitudes toward, the guidelines. Although only 17.6 per cent reported having a friend with AIDS, 64.9 per cent had a visual image of AIDS deterioration—a factor which was related to behavioral risk reduction. These results provide evidence that, comparatively early in the epidemic, knowledge was far from complete and that the salience of the epidemic also seemed to be subject to individual variability. Insofar as metropolitan areas such as San Francisco experienced manifestations of the epidemic in an earlier or more extreme form, this suggests that provision of adequate information and communication about risk may be early needs.

As part of their efforts to determine the magnitude and determinants of behavioral risk reduction in Chicago, Joseph and others[31,32] constructed indices to assess the levels of AIDS knowledge and perceived risk. Knowledge, which appeared to be more important in predicting initial or accumulated behavioral risk reduction rather than its maintenance or incremental improvement, was assessed using a multi-item index that summed seven items dealing with the etiologic agent for AIDS, mechanisms of transmission, and public health behavioral recommendations. Because both transmission and prevention issues were combined in this index, it is not possible to describe separately the prevalence of particular types of knowledge. However, the global knowledge mean score was 71.4 per cent. Perceived risk of AIDS was not related in any straightforward fashion to either cross-sectional or longitudinal findings. In a separate report, this group suggests that the relatively facile notion that a sense of risk will improve compliance to behavioral recommendations requires more careful examination.[59] Nonetheless, they note that the mean score on a perceived risk index was 44.4 per cent, or less than "some" or an "average" chance of getting AIDS. Approximately 40 per cent of this cohort was already seropositive at the time of recruitment,[60] so there appears to be an optimistic bias regarding personal risk of AIDS. On the other hand, when men in the cohort were given the opportunity to affirm their belief that biomedical technology will provide a vaccine or cure in the near future, the mean score for this index was only 40 per cent; this suggests that although the sense of risk may be optimistically understated, it is not because respondents assume they will be rescued by technological innovations. Men were, however, fairly certain that behavioral changes are effective in reducing the risk of AIDS; this index had the highest overall mean score (82 per cent). Similarly, men reported sexual norms in their peer culture as generally supportive of adherence to behavioral risk reduction guidelines (mean score=64 per cent). Taken together, these results imply that, even in a lower-risk area, knowledge and attitudes are generally supportive of behavioral risk reduction. On the other hand, the uniquely advantaged nature of this cohort needs to be kept in mind, and it is clear that considerable variability remains even in this group of highly motivated and well educated men.

A study more directly concerned with attitudes in homosexual and bisexual men is reported in a Pittsburgh-based investigation by Valdiserri and others.[61] A cohort of 1,700 men enrolled in a natural history study of HIV infection was invited to participate in an educational session as part of the process of learning their HIV serologic status; 464 (32 per cent) agreed to do so. Serologic status did not distinguish participants and non-participants.

Prior to the intervention, knowledge was high concerning transmission of AIDS, AIDS risk groups, HIV natural history, manifestations of HIV infection, and the meaning of HIV antibody testing; men were somewhat less well informed regarding local AIDS prevalence. The majority of respondents also endorsed attitudes supportive of AIDS risk reduction, although a sizable minority did not. Strongest agreement (71 per cent among participants) concerned statements endorsing decreases in number of sexual partners, while items describing discussion of AIDS prevention with sexual partners received the lowest scores (53 per cent among those participating).

Given the relatively high initial scores, knowledge scores were predictably unchanged at the post-intervention assessment, but altered attitudes were observed in five of the six domains assessed. No changes were seen in any of the eight statements that assessed attitudes regarding number and type of sexual partners. No analysis of the relationship of attitudinal change to sexual practices was reported; however, both among those who participated in the intervention and those who declined to do so, nearly two-thirds indicated unprotected receptive anal intercourse with more than one partner in the preceding six months. Given the remarkably complete knowledge regarding AIDS in this cohort, this suggests that it is not information but, rather, attitudes or other factors which need to be targeted in future intervention activities.

The special needs of the minority (especially black) homosexual/bisexual male population are becoming increasingly recognized.[62] In this regard, a series of 62 interviews conducted by a Black community group in Detroit is of special relevance.[63] No sociodemographic data are provided, but the purpose of the study was to assess needs in the Black community where many homosexuals remain "closeted" and therefore difficult to reach even in surveys of th homosexual community. While 58 per cent of the respondents were able to correctly identify IVDUs as being at risk for AIDS, only 13 per cent knew that semen and blood were primary routes for transmission of HIV. No information is given about the proportion of the sample who knew that HIV could be transmitted in homosexual male intercourse, although 37 per cent identified Haitians as a high-risk group. The preventive methods mentioned most often were monogamy and frequent medical checkups (no data provided). Almost three-fourths either felt that information in the Black homosexual community regarding AIDS was inadequate or were unsure about the availability of such information. The local organization providing AIDS-related preventive and service efforts was seen as a source of information by fewer than 7 per cent of the sample. Only 19 per cent of the participants were very worried that they might get AIDS, while 37 per cent reported that they were not worried (the remaining 44 per cent were somewhere intermediate between these extremes).

Knowledge and Attitudes in IV Drug Users

Friedman documented level of knowledge concerning AIDS as well as relevant behaviors in 59 Manhattan methodone maintenance patients.[40] All knew of AIDS, 93 per cent knew that IVDU was a mechanism for transmission, and 61 per cent were able to correctly identify at least one symptom of AIDS. Friedman also reports work by Selwyn and others in their sample of 146 methadone maintenance patients and 115 incarcerated drug users in New York City. During 1985, 97 per cent of these participants knew that you can get AIDS from sharing needles, although inaccurate information was also comparatively widespread (e.g., a majority of a sample believed that you could acquire AIDS from sharing a drinking cup). Knowledge of preventive methods was not specifically discussed, but the behavioral changes observed suggest that the participants are familiar with the need to eliminate needle-sharing and/or to clean needles when they are shared.

Ginzburg and others presented results of a knowledge assessment survey among IVDUs in both 1984 and 1985.[45] During 1984, more than 1,000 IVDUs from 10 drug treatment programs in New Jersey were invited to participate in a study designed to determine seroprevalence of HIV infection and level of knowledge in the surveyed communities. The authors report that less than 5 per cent of those approached refused to cooperate. Level of knowledge was unrelated to variability in community AIDS prevalence. Almost all participants were aware that IVDU increased the risk of infection with HIV and that this was due specifically to the practice of needle-sharing, with 93 per cent correctly identifying means of avoiding AIDS (the exact content of this question is not further specified).

A similar survey was undertaken a year later among those entering treatment; 89.1 per cent correctly identified IVDUs as a risk group and 87 per cent knew that the virus is spread by sharing needles. While only 29.3 per cent correctly identified the use of a 10 per cent solution of bleach as a method for sterilizing needles and reducing risk of transmission, 81.8 per cent correctly reported that never sharing needles or syringes would lower the risk of AIDS.

In this same group, approximately one-third did not recognize the potential for transmission of HIV from the intravenous drug user to his or her heterosexual partner. Perhaps more worrisome is that 43 per cent failed to recognize that infants born to women who use IV drugs (or whose partners do) are at risk for AIDS. There was considerable misinformation in this group as well: 16.3 per cent of those surveyed believed that living in a home or working with someone who has AIDS is sufficient to transmit the illness and 15 per cent felt that wiping off a needle before use was sufficient to reduce the risk of AIDS. Furthermore, just over one-third thought that those who were infected with the AIDS virus would be visibly ill—an especially problematic notion because it would suggest that needle sterilization techniques might be directed only at drug partners who were not well. The authors point out that the concept of a carrier state may be a particularly difficult one for a group where physical appearance alone is often sufficient to permit recognition of those with hepatitis, a situation quite different from that of AIDS.

Information from Detroit methadone maintenance programs is supplied by Williams.[63] All respondents were Black as the particular focus of this group was the development of materials and programs appropriate for use in the Black population at risk for AIDS. Knowledge regarding AIDS and the transmission of HIV among homosexual men was at least adequate, yet only 62 per cent described IVDUs as a high-risk group. Blood and semen were correctly identified as the principle mechanisms for transmission, but 57 per cent were not concerned that they might get AIDS, and only 11.2 per cent were "very worried" about developing AIDS. Avoidance of IVDU was identified as an effective preventive by 6 per cent of those surveyed, and no longer sharing needles by 67 per cent. No data were available concerning use of a dilute bleach solution for inactivation of HIV. More than half were unaware of where they might call to receive more information, and 93.8 per cent believed such information should be available from drug treatment centers. Taken together, these facts suggest that perceived vulnerability and preventive knowledge were far from complete in this population, and that there was considerable potential for further intervention.

Knowledge and Attitudes in Other Groups

Using a brief self-administered questionnaire, Price and others investigated level of AIDS knowledge in a sample of 250 Ohio adolescents.[64] Although between half and three-fourths of these high school junior and senior students knew about certain characteristics of AIDS (immune suppressive syndrome, new disease, no cure), they were not able to correctly identify all risk groups, nor did they understand transmission. Overall, students who performed best nonetheless answered only 47 per cent of the questions correctly. Sources of information used by the students demonstrate that those using magazines were the best informed, with television and newspapers ranking second and third, respectively. Perceived vulnerability was assessed by asking students if they were worried about getting AIDS. Only 27 per cent indicated that this was the case, and fewer males than females were "personally worried" about contracting AIDS.

In San Francisco, DiClemente and others[65] evaluated knowledge, beliefs regarding personal vulnerability, and perceived need for AIDS instruction in high schools. General characteristics of the syndrome were correctly identified by the majority of students. While 92.4 per cent recognized "having sex with someone" and 81.1 per cent identified "sharing a needle with a drug user" as modes of transmission, almost one-fourth either believed that shaking hands with someone could give you AIDS or were unsure on this point. Only 60.0 per cent of the students knew that using a condom during sex could help prevent AIDS, and three-fourths thought a new vaccine might have been recently developed for the treatment of AIDS.

On the other hand, these students appeared (perhaps because they reside in San Francisco) to be concerned about AIDS; 78.7 per cent reported that they were afraid of getting AIDS, and 41.8 per cent believed that their chances of getting AIDS were increased by living in the San Francisco area. Conversely, when students were asked if they felt they were less likely than most people to get AIDS, 52.5 per cent students agreed, and 61.5 per cent believed they were "not the kind of person" who is likely to get AIDS. It is difficult to know if these statements reflect an accurate assessment of their sexual and drug behaviors or an over-optimistic bias.

Strunin and Hingson's[53] survey in Massachusetts indicated that 96 per cent of adolescents had heard of AIDS and almost 50 per cent had discussed the subject with their parents or other adult family members; nonetheless, considerable confusion remained regarding the transmission of AIDS and, more particularly, regarding the meaning of "bodily fluids." Although only 4 per cent of the respondents knew someone who was or had been ill with AIDS, 11 per cent of these believed those with AIDS were contagious and had therefore seen the person less. Similarly, 23.2 per cent believed that someone with AIDS should not be allowed to attend school because of the potential for transmission. With regard to perceptions of risk, 54 per cent of the respondents were not at all worried that they might contract AIDS, and 61 per cent did not think it at all likely that they would get AIDS in their lifetime.

In a study of 212 college-age young adults in Kansas City,[55] Simkins and Kushner found that 71 per cent of the respondents indicated they were not concerned about contracting AIDS from their present sexual partner, and 41 per cent had no concerns regarding any future partners. As might be expected, there was more concern expressed by the small number of homosexual respondents, and men were more concerned about their partners infecting them with AIDS than were women. A homophobia scale was administered and found to correlate at a relatively low level with concerns regarding transmission of AIDS from either present (r=.18) or future partners (r=.22). Only one-fourth of respondents indicated that AIDS was of concern to them and that this had influenced changes in their sexual behavior. Despite the marked difference in lethality of the two conditions, students were equally concerned about herpes and AIDS; this may reflect the comparative prevalence of the two conditions in college-age populations rather than erroneous risk perceptions.

Reports from the United Kingdom provide evaluations of public information campaigns about AIDS. Sherr and others present data from both higher-risk individuals (patients at a clinic for sexually transmitted disease) and lower-risk individuals (law students and patients at a general practice office).[66] These groups were surveyed before any public information campaign; after an initial series of advertisements; and after a second series. Following the first advertisement, 41.9 per cent of the respondents indicated that they had read it, while 24.1 per cent reported reading the second. No details are provided, but the authors state that "information levels" were increased after both advertisement campaigns. They note, however, that although knowledge was increased, misconceptions were not corrected (i.e., error scores remain constant), and anxiety was not lowered by either program.

In Scotland, focus group qualitative research methods were used to assess knowledge and attitudes toward AIDS as part of the development of a public information leaflet. Participants correctly saw AIDS as a sexually transmit disease that could also be transmitted through blood contac However, most believed that social contact was also sufficient for transmission, either through sharing facilities (such as a common cup) or through social interaction (shaking hands). Although respondents were able to correctly identify homosexual men and IVDUs as groups at higher risk, these groups were seen as being different from "ordinary" people, and affective responses to them were "profoundly negative." These negative feelings were generalized to the condition of AIDS, which was seen both as shameful and only affecting those with idiosyncratic behaviors.

Discussion

It is evident from the literature reviewed that changes in human behavior are occurring because of the threat of AIDS. Indeed, in some populations of homosexual/bisexual men, this may be the most rapid and profound response to a health threat which has ever been documented. The most complete data illustrating this point are available in San Francisco, where three separate cohorts are being studied and behavioral information is available from 1982 through 1986. Although cautions must be expressed about the comparability of these descriptions, an overall picture nonetheless emerges concerning the crucial transmission behavior of unprotected anal intercourse. In 1982, somewhere between 40 per cent and 60 per cent of San Francisco homosexual men appear to have been exposing themselves to HIV in this fashion.[24] By 1983, the prevalence of this behavior had declined to 30.2 per cent among those who were non-monogamous, while 59.1 per cent of monogamous men continued the behavior. A sec study documented an 18 per cent prevalence of unprote anal intercourse with non-primary partners, with a decrea to 12 per cent by 1985.[28] Also in 1985, receptive anal intercourse among the still vulnerable seronegatives was reported by 14 per cent of another cohort, but this figure had declined to 5.8 per cent by 1986.[24] In a parallel fashion, insertive anal intercourse prevalence dropped from 39.6 per cent in 1985 to 13.8 per cent in 1986 (these data do not take into account condom usage, so that effective transmission of HIV is presumably even less common). Taken together, these data suggest what may be a 90 per cent reduction in a powerfully reinforcing, common, and habitual behavior during a four-year period.

Available evidence also suggests that IVDUs are changing their behaviors. In sharp contrast to common stereotypes, a variety of behavioral changes were reported by 59 per cent of methadone maintenance patients as early as 1984 in New York City.[40] Furthermore, novel behaviors such as use of bleach solutions to disinfect needles and syringes increased eight-fold during two years and were reported by almost half of those interviewed in 1987.[43] It is among potentially vulnerable adolescent and young adult heterosexuals that little change is yet documented. Available data are limited, but suggest urban Black and Hispanic populations are also experiencing less behavioral change.

It is also apparent that there are preferred strategies being employed for risk reduction. As suggested in the introduction to this review, those at risk can either eliminate or modify behaviors that promote transmission of HIV; this is equally true for sexual and for drug-use behaviors. It is hardly surprising to note that celibacy is not the pref strategy of homosexual/bisexual men for dealing with the f AIDS. Instead, they appear to be differentially reducing their number of sexual contacts outside of a primary relationship and/or to be eliminating or modifying anal intercourse by use of condoms. Similarly, IVDUs are purchasing new needles or syringes, and learning to sterilize their equipment when sharing it. Apart from the scientific merit of accurately describing these preferences, we suggest that they might also inform the development of intervention programs. Although it may be attractive to counsel abstinence, information and support need to be provided to the much larger group of individuals who are choosing to modify their behavior. This immediately creates the difficulties in developing a social consensus which were discussed earlier. There are those for whom such programs provide tacit approval of behaviors which they view as at least illicit if not immoral. Nonetheless, we must consider the public health and social consequences of a failure to recognize how behavior change is most likely to occur.

On the other hand, the idiosyncratic nature of this infectious syndrome creates special problems. Unlike chronic diseases in which accumulated exposure produces deleterious health effects, in the case of AIDS we are concerned with avoiding probabilistic exposure to a retrovirus. Both the seroprevalence of this virus in a subgroup and the behaviors which they share will influence the likelihood of transmission. This virological reality creates special problems. For example, in a subgroup where HIV infection is comparatively uncommon, advice to limit frequency of exposure (e.g., by reducing the number of sexual or needle-sharing contacts) may have some value since it effectively reduces likelihood contact with an infected person. However, as seroprevalence rises, this strategy becomes less likely to succeed. Indeed, even the suggestion that risky activities are permissible within the confines of a mutually monogamous relationship is patently hazardous unless serostatus is absolutely concordant and behavior is absolutely monogamous (and even this strategy ignores technological and human fallibility as well as the possibility of infection with other agents). Concern must then be expressed about the apparent distinction among homosexual/bisexual men between what is permitted within a primary relationship and what is allowed outside such a relationship. It would seem imperative that the simple but emphatic educational message emphasize preventing exposure to potentially infectious blood and semen. Thus, safer sex is not conditional on partner choice but requires altering behaviors with all partners. This is of even greater concern for heterosexuals, where behavioral responses such as "being careful" in partner choice are distressingly common.

Control of HIV transmission also requires that changes in behavior be applied consistently. There is ample evidence in these studies of recidivism (i.e., instability in behavioral risk reduction). Although a common phenomenon with any health behavior, it is potentially lethal in the case of AIDS. This may argue against attempts to eliminate rather than to modify transmission-relevant behaviors; if the probable outcome of such extreme change is subsequent readoption of high-risk behaviors, there is little to be gained by such a strategy. We recognize that positive health behaviors are often adopted incrementally, and with inevitable periods of "backsliding". Tragically, in the case of AIDS, these expectable patterns have potentially lethal consequences. At a minimum, it would seem necessary to strengthen and clarify behavioral recommendations so that the message of "risk reduction for a lifetime" takes center stage. This also suggests that community service programs need to anticipate the need for reinforcing and maintaining behavior change as well as for initiating it.

The discussion has, to this point, been primarily concerned with reducing an individual's risk of infection with HIV; however, the public health concern is inevitably somewhat different. Here, the question is not how an individual might avoid risk but how a population might avoid further transmission of an infectious agent. This draws attention to the problems created by even a small group of individuals who maintain behaviors capable of transmitting HIV. While behavioral risk reduction has been widespread, it is certainly not complete. Even the simplest transmission models suggest that a small group of particularly active individuals may be sufficient to prolong and/or extend this epidemic. Having said this, the immediate question becomes why most individuals successfully change their behaviors while some others do not. Unfortunately, distressingly little attention has been paid to this central issue. Further studies simply documenting the magnitude of behavioral change are of little value in most populations. What is required are vigorous attempts to better understand the determinants of AIDS-relevant behavioral change. Such observational studies are an essential prerequisite for the development of potentially successful intervention programs. Until we can describe and address the impediments to behavioral change, discussion of such extreme policies as quarantine or isolation of those infected will continue. To call for quarantine is, in essence, to announce that we have given up in our attempts to facilitate behavior change. Evidence reviewed here suggests this is certainly not necessary, but virtually no attention has been paid to the key issue of understanding behavioral risk reduction. The effort to recruit and assess those at risk for AIDS has been enormous; future work *must* capitalize on this investment by adequately investigating the determinants of behavior.

Finally, this review highlights the need to diversify research activity by including investigations of minority populations and young adults. The special needs of these groups are now being recognized, but carefully developed and rigorously analyzed behavioral studies are imperative. At a minimum, it is naive to assume that studies in population subgroups can simply be extrapolated to others; for example, the determinants of condom use among homosexual males, intravenous drug users, and inner city adolescents may be quite dissimilar.

This report has also reviewed studies of AIDS-relevant knowledge and behavior which, taken together, suggest at least an ecological correlation between level of knowledge and extent of behavior change in various groups. It would seem that homosexual/bisexual men are the best informed and the most likely to change their behavior, while the opposite is true of late adolescent and young adult heterosexuals. Nonetheless, there is little actual evidence that an individual's knowledge and attitudes toward AIDS significantly shape his or her behavior. It may well be that there is some "threshhold" effect and that, beyond a certain level, further increments in knowledge or improved attitudes no longer influence behaviors. On the other hand, it is also possible that this ecological association is an indirect one and that some third factor, such as comparative social advantage, provides the major link between positive knowledge/attitudes and behavioral risk reduction. In any event, these uncertainties only serve to highlight the need for further studies of the determinants of behavioral risk reduction.

In conclusion, we wish to reemphasize the multifaceted and complex nature of the problem presented by the AIDS epidemic. There is an urgent requirement for interdisciplinary investigations which attend to behavioral as well as biomedical issues. After six years of experience with this epidemic, we still know far too little about behavioral and human responses to it.

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The Global AIDS Situation: WHO Update, January 1988

The numbers of reported cases of AIDS and countries reporting AIDS have continued to increase dramatically. As of January 1, 1988, 73,747 AIDS cases have been officially reported to the World Health Organization (WHO) from 129 countries. However, the total number of AIDS cases to date is estimated to be approximately 150,000.

- WHO estimates that between 5 and 10 million persons may be currently infected with human immunodeficiency virus (HIV), the virus which causes AIDS. By 1991, WHO estimates that at least one million new cases of AIDS could develop in people already infected with HIV.
- AIDS has been reported from every part of the world. The largest number of cases, 48,139, have been reported in the United States, where the disease was first recognized in 1981. In 41 other countries in the Americas, a total of 7,215 cases have been reported. In the Americas, Europe and Australia, most AIDS cases occur among young, 20–49 year-old homosexual or bisexual men and intravenous drug users. However, the estimate of the proportion of cases of AIDS acquired through heterosexual contact has increased from 1% to approximately 4%.
- In Europe, where 27 countries have reported 8,839 AIDS cases, most countries are now considered to be facing an epidemic. WHO estimates that 500,000 to one million persons in Europe are infected with the AIDS virus. Highest per capita cases of AIDS are found in Switzerland, Denmark, France and Belgium. WHO estimates 25,000 new cases of AIDS in Europe by the end of 1988.
- In Africa, the number of countries reporting AIDS to WHO has increased substantially in the past year. As of January 1, 37 African nations had reported 8,652 cases of AIDS. Major factors of HIV spread in Africa are heterosexual transmission, transfusions with unscreened blood, use of unsterilized needles or syringes, and mother-to-child transmission. The latter is a significant source of infection, especially in areas where 5–10% of pregnant women have been recorded as HIV seropositive.
- In Asia, 19 countries have reported 224 cases of AIDS. Many of those cases are linked to persons who have been in areas where AIDS is more prevalent. Oceania (including Australia and New Zealand) has reported 742 cases.
- The WHO Special Program on AIDS (SPA) was established on February 1, 1987 as the headquarters of the global fight against AIDS. As of January 1, 1988, SPA received requests for collaboration from 132 countries. Initial support of national AIDS programs has been carried out in 109 countries with more scheduled. In concert with SPA, 70 countries have completed short-term (6–12 month) plans; 26 countries have completed medium-term (3–5 year) plans; national AIDS committees have been established in more than 150 countries.

The global AIDS strategy of the Special Program on AIDS has been endorsed by the World Health Assembly (May 1987), at the United Nations General Assembly (October 1987), the Economic and Social Council of the United Nations (July 1987), and the Venice Summit (June 1987). The address of the World Health Organization is 1211 Geneva 27 Switzerland.

Perceived Self-Efficacy in the Exercise of Control Over AIDS Infection

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Prevention of infection with the AIDS virus requires people to exercise influence over their own motivation and behavior. Social efforts designed to control the spread of AIDS have centered mainly on informing the public on how the human immunodeficiency virus (HIV) is transmitted and how to safeguard against such infection. It is widely assumed that if people are adequately informed about the AIDS threat they will take appropriate self-protective action. Heightened awareness and knowledge of health risks are important preconditions for self-directed change. Unfortunately, information alone does not necessarily exert much influence on refractory health-impairing habits. It has not slimmed the obese, eradicated cigarette smoking despite its acknowledged hazard for cancer, respiratory disorders and heart disease, nor has it made a substantial dent on nutritional patterns that create high risk of cardiovascular disease in those who need to change most. It certainly will not make the sexually active celibate and impel intravenous drug users to renounce drugs, which are the two major transmitter modes for the AIDS virus.

To effect self-directed change, people need to be provided not only with reasons to alter risky habits but also with the means and resources to do so. Effective self-regulation of behavior is not achieved by an act of will. It requires certain skills in self-motivation and self-guidance (Bandura, 1986). Moreover, there is a difference between possessing coping skills and being able to use them effectively and consistently under difficult circumstances. Success, therefore, requires not only skills, but also strong self-belief in one's capabilities to exercise personal control.

Perceived self-efficacy is concerned with people's beliefs that they can exert control over their motivation and behavior and over their social environment. People's beliefs about their capabilities

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affect what they choose to do, how much effort they mobilize, how long they will persevere in the face of difficulties, whether they engage in self-debilitating or self-encouraging thought patterns, and the amount of stress and depression they experience in taxing situations. When people lack a sense of self- efficacy, they do not manage situations effectively even though they know what to do. Self-misgivings create discrepancies between knowledge and action.

Numerous studies have been conducted linking perceived self-efficacy to health-promoting and health-impairing behavior (Bandura, 1986; 1987a; O'Leary, 1985a). The results show that perceived efficacy can affect every phase of personal change--whether people even consider changing their health habits, how hard they try should they choose to do so, and how well they maintain the changes they have achieved. In addition to influencing health habits, perceived coping inefficacy increases vulnerability to stress and depression and activates neurochemical changes that can affect various facets of immune function (Maier, Laudenslager, & Ryan, 1985).

Translating health knowledge into effective self-protection action against AIDS infection requires social skills and a sense of personal power to exercise control over sexual situations. As Gagnon and Simon (1973) have correctly observed, managing sexuality involves managing interpersonal relationships. Problems arise in following safer sex practices because self-protection often conflicts with interpersonal pressures and sentiments. In these interpersonal situations the sway of coercive power, allurements, desire for social acceptance, and fear of rejection and personal embarrassment can override the influence of the best of informed judgment. The weaker the perceived self-efficacy, the more such social and affective factors can increase the likelihood of risky sexual behavior.

Exercise of personal control over sexual situations that carry risk of infection calls on skills and self-efficacy in communicating frankly about sexual matters and protective sexual methods and ensuring their use. Some of the people who perceive a personal risk of sexually transmitted disease are reducing the number of sexual partners and are more wary of engaging in sex with casual partners. Ignorance of a partner's sexual and drug activities has become a new risk factor. However, to rest self-protection on partners' reports of their sexual and drug history is a hazardous safeguard. Sexual ardor and impression management can readily expurgate risky histories in personal disclosures. Survey studies reveal that even a majority of monogamous relationships are so in name rather than in actual practice. With increased heterosexual transmission of the AIDS virus, occasional sex with a partner outside a monogamous relationship, especially one who has had bisexual or drug involvements, expands the range of potential risk.

Risk appraisal for AIDS infection is highly unreliable when the relevant risk factors remain concealed. Lacking knowledge of the behavioral history and serostatus of sexual partners, people tend to make their risk appraisals on the basis of social and physical appearances, which can be quite misleading because infected persons often remain asymptomatic for a long time. Even those who are well informed on safer-sex guidelines often err in their subjective appraisal of the extent to which they are putting themselves at risk of HIV infection. Bauman and Siegel (1987) found that gay men practicing hazardous sex underestimate the riskiness of their behavior as judged against epidemiologically established linkage to seropositivity. Misappraisals of riskiness of one's sexual practices tend to be associated with underestimation of personal susceptibility to infection and with misbeliefs that risky sex with a few regular partners is safe and that behavioral precautions that actually have no protective value (showering before and after sexual contact, healthful regimens, inspecting partners for lesions) will render risky sex safe. Such findings underscore the need for risk-reduction messages to describe not only risky sexual practices but also the common misbeliefs about factors that invest the practices with false safety.

In managing sexuality, people have to exercise influence over themselves as well as over others. This requires self-regulatory skills in guiding and motivating one's actions. Self-regulation operates through internal standards, affective reactions to one's conduct, use of motivating self incentives and other forms of cognitive self-guidance. Self-regulatory skills thus form an integral part of risk-reduction capabilities. They partly determine the social situations into which people get themselves, how well they navigate through them, and how effectively they can resist social inducements to potentially risky behavior. It is easier to wield control over preliminary choice behavior that may lead to troublesome social situations than to try to extricate oneself from such situations. This is because the antecedent phase involves mainly anticipatory motivators which are amenable to cognitive control; the entanglement phase includes stronger social inducements to engage in high-risk behavior which are less easily manageable.

Control of the spread of the AIDS virus by intravenous drug users requires risk-reduction strategies aimed at both drug and sexual practices. Relatively little effort has been devoted to developing interventions to prevent infection among intravenous drug users. This is a serious neglect because infected drug users are transmitting the virus heterosexually to their female sexual partners who, in turn, run a high chance of infecting their infants through perinatal transmission. As a result, AIDS is taking an increasingly heavy toll on women and children, especially among ethnic minorities in impoverished environs where drug use is prevalent. Those who continue to inject drugs intravenously, despite cognizance of the threat of AIDS infection, need access to sterile needles and knowledge on how to disinfect needles to safeguard against transmission of the virus. They need to be taught protective sexual practices to avoid infecting their sexual partners and persuaded to use them.

Perceived Self-Efficacy and Adoption of Health Practices

People's beliefs that they can motivate themselves and regulate their own behavior plays a crucial role in whether they even consider altering habits detrimental to health. They see little point to even trying if they believe they cannot exercise control over their own behavior and that of others. Even people who judge their health to be highly susceptible to impairment by their detrimental habits achieve little success in curtailing their behavior unless they judge themselves as having some efficacy to resist the instigators to it. This is corroborated in a longitudinal study conducted by McKusick, Wiley, Coates, and Morin (1986) of gay men's sexual behavior. Several psychological factors that could influence sexual risk-taking behavior were assessed. These included perceived threat that one is potentially at risk of exposure to the AIDS virus; degree of peer support for adopting low-risk sexual behavior ; social skills necessary to negotiate protective sexual behavior; level of self-esteem; and perceived self-efficacy that one is capable of taking protective actions that lessen the risk of AIDS infection.

The spreading threat of AIDS produced some change in sexual practices as shown in reduction of high-risk sexual acts and number of sexual partners. Perceived self-efficacy emerged as the best predictor of sexual risk-taking behavior. The lower the perceived self-efficacy, the higher the likelihood of engagement in sexual practices that carry a high risk of AIDS infection. Men who frequented bars and bath houses had a lower sense of efficacy than those who were committed to a monogamous relationship. Social skill in negotiating protective sexual activity was also associated with low-risk sexual practices.

Framing Health Messages. Efforts to get people to adopt health practices rely heavily on persuasive communications in health education campaigns. In such health messages, appeals to fear by depicting the ravages of disease are often used as motivators, and recommended preventive practices are provided as guides for action. People need enough knowledge of potential dangers to warrant action, but they do not have to be scared out of their wits to act, any more than homeowners have to be terrified to insure their households. Rather, what people need is sound information on how AIDS is transmitted, knowledge about how to regulate their behavior, and firm belief in their personal efficacy to turn concerns into effective preventive actions. This requires a shift in emphasis from trying to scare people into healthy behavior to empowering them with the tools for exercising personal control over their health habits.

The influential role of people's beliefs in their personal efficacy in adopting preventive health practices is shown by Beck and Lund (1981). They studied the persuasiveness of health communications in which the seriousness of a disease, and susceptibility to it, were varied. Patients' perceived efficacy that they could stick to the required preventive behavior was a good predictor of whether they adopted the preventive practices. Fear arousal had little effect on whether or not they did so. Slater (1986) has similarly found that perceived self-efficacy plays an influential role in the social diffusion of health practices promoted by mass media campaigns. The stronger the perceived self-efficacy, the more likely people are to adopt the recommended practices. The relationship remains even when multiple controls are applied for a host of other possible influences.

To be most effective, health communications should instill in people the belief that they have the capability to alter their health habits and instruct them on how to do it. Communications that explicitly do so increase people's determination to modify habits detrimental to their health (Maddux & Rogers, 1983). Entrenched habits rarely yield to a single attempt at self-regulation. Success is usually achieved through renewed effort following failed attempts. To strengthen the staying power of self-beliefs, health communications should emphasize that success requires perseverant effort so that people's sense of efficacy is not undermined by a few setbacks. Unfortunately, the possibility that the AIDS virus is transmittable to the immunologically vulnerable through a single sexual contact with an infected partner or sharing a contaminated needle does not leave much room for carelessness.

An increased research effort is needed to determine how preventive health communications should be framed to maximize their impact on perceived self-regulatory efficacy. Self-efficacy theory provides one set of guidelines (Bandura, 1986). We shall consider later how symbolic modeling influences should be structured to maximize their impact. Decision theory regarding risk perception and risky decisions provides other suggestions (Tversky & Kahneman, 1981). For example, people interpret information regarding risky activities in terms of potential gains and potential losses. Persuasive communications have differential impact on perceived self-efficacy depending on whether they are framed in terms of gains or losses. Communications phrased in terms of benefits are less effective in altering detrimental habits than communications phrased in terms of personal losses. Examination of possible mediating mechanisms shows that the more persuasive messages achieve their effects by raising perceived self-efficacy rather than by heightening fear or perceived threat (Meyerowitz & Chaiken, 1987). In designing national education campaigns we need to exploit our knowledge of social influence processes and the cognitive and affective mechanisms governing human motivation and behavior.

Components of Effective Self-Directed Change

An effective program of widespread change in detrimental lifestyle practices includes four major components. The first is informational, designed to increase people's awareness and knowledge of health risks. The second component is concerned with development of the social and self-regulatory skills needed to translate informed concerns into effective preventive action. The third component is aimed at skill enhancement and building resilient self-efficacy by providing opportunities for guided practice and corrective feedback in applying the skills in high-risk situations. The final component involves enlisting social supports for desired personal changes. Let us consider how each of these four components would apply to self-directed change of behaviors that pose high risk of AIDS infection.

Informational Component

The preconditions for change are created by increasing people's awareness and knowledge of the profound threat of AIDS. They need to be provided with a great deal of factual information about the nature of AIDS, its modes of transmission, what constitutes high risk sexual and drug practices, and how to achieve protection from infection. This is easier said than done. Our society does not provide much in the way of treatment of drug addiction, nor is about to provide refractory drug users with easy access to sterile needles and other drug paraphernalia. It does not have much experience in how to reach and educate drug users on how to disinfect needles to reduce the risk of AIDS infection.

In the sexual domain, our society has always had difficulty talking frankly about sex and imparting sexual information to the public at large. Since parents generally do a poor job of it as well, most youngsters pick up their sex education from other, often less trustworthy and reputable, sources outside the home or from the consequences of uninformed sexual experimentation. To complicate matters further, some sectors of the society lobby actively for maintaining a veil of silence regarding protective sexual practices on the belief that such information will promote indiscriminate sexuality. In their view, the remedy for the spreading AIDS epidemic is a national celibacy campaign for unweds and gays and faithful monogamy among the wedded. They oppose educational programs in the schools that talk about sex methods that provide protection against AIDS infection.

The net result is that many of our public education campaigns regarding AIDS are couched in desexualized generalities that leave some ignorance in their wake. To those most at risk, such sanitized expressions as "exchange of bodily fluids" is not only uninformative but may invest safe bodily substances with perceived infective properties. Even those more skilled in deciphering medical locutions do not always know what the preventive messages are talking about. For example, an intensive campaign spanning a full week was conducted on the Stanford campus, including public lectures, numerous panel discussions, presentations in dormitories, and condom distribution, all of which were widely reported in the campus newspaper. A systematic assessment of students' beliefs and sexual practices conducted several weeks later revealed that more than a quarter of the students did not know what constitutes "safer sex," and some of them had misconceptions of safer sex practices that, in fact, would present high risk of infection. Other findings of this study, which will be reviewed later, underscore the severe limitations of efforts to change sexual practices by information alone.

The informational component of the model of self-directed change includes two main factors--the informational content of the health communications and the mechanisms of social diffusion. Detailed factual information about AIDS must be socially imparted in an understandable, credible, and persuasive manner. Social cognitive theories provide a number of guidelines on how this might be best accomplished (Bandura, 1986; Cialdini, 1985; McGuire, 1964; Zimbardo, Ebbesen, & Maslach, 1977). It is one thing to develop effective AIDS prevention programs. It is another thing to get them disseminated. Unlike other health risk-reduction campaigns which involve relatively prosaic habits, the risky habits for

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AIDS infection are laden with matters of illegalities and judged immoralities.

Informative health messages, however well designed, cannot have much social impact without effective means of dissemination. Because of their wide reach and influence, the mass media, especially television, can serve as a major vehicle of social diffusion of information regarding health guidelines. However, a variety of diffusion vehicles must be enlisted in a public health campaign for several reasons. High costs and restricted access to television limit its availability. Moreover, television networks have resisted getting into the act for fear that talk of protective sex practices will jeopardize advertising revenue by arousing the wrath of some sectors of their viewing audience. This resistance may eventually weaken as the AIDS virus is increasingly transmitted heterosexually, thus making it a general societal problem rather than one confined to gays and drug users. Existing social, religious, recreational, occupational, and educational organizations can serve as highly effective disseminators of preventive health guidelines. Wide cultural diversity requires that the messages of risk-reduction campaigns for AIDS be tailored to socioeconomic, racial and ethnic differences in value orientations and disseminated through multiple sources to ensure adequate exposure (Mantell, Schinke, & Akabas, 1988).

Nontraditional social networks must be enlisted for high-risk groups who are beyond the reach of the usual community organizations. For example, in an educational program in San Francisco, "street-wise" counselors have been highly successful in reaching drug populations (Watters, 1987). After they become known in the social circles of drug users, the counselors help them with referrals to drug treatment programs. They offer them explicit instruction in safer sex practices. They teach intravenous drug users how to reduce the risk of AIDS by disinfecting needles with ordinary household bleach which kills the HIV virus. The disinfection procedure, which had been rarely used before, was widely adopted and consistently applied. Although this outreach program also increased the use of condoms, the drug users were much more conscientious in disinfecting needles than in protecting their sexual partners against sexually transmitted infection. Such findings underscore the need for sexual partners to exercise personal control in protecting their own health.

A comprehensive national program regarding the growing AIDS threat must address broader social issues as well as risky health practices. This is because the AIDS epidemic has far-reaching social repercussions. One of these issues concerns the widespread public fear of AIDS infection. Many people continue to believe that the AIDS virus can be transmitted by casual contact or by insect transmission and food handling despite evidence to the contrary. Efforts by health professionals to dispel misapprehensions are discounted by many of those who are alarmed on the grounds that what is proclaimed safe currently may be discovered to be risky later. Fear gets translated into advocacy of laws requiring sweeping mandatory blood testing and identification and social restriction of those with antibodies to the HIV virus.

As AIDS imposes mounting financial burdens on society and strains medical and social service systems, members of high-risk groups may become targets of growing public hostility. Once entire groups get stigmatized because some of its members behave in high-risk ways, those who do not also become the objects of fear and hostility. Their social treatment may be dictated more by group identity than by their personal characteristics. Public alarm fueled by many misbeliefs enhances such stigmatization. Policy debates on how to control the spread of AIDS have become highly politicized. Prohibitionists argue that public health campaigns promote indiscriminate sex. Their critics argue that knowledge does not foster sexuality and that prohibitionists are intent at curtailing sex practices they find morally objectionable rather than at increasing the safety of sex. Uninformed public reactions to the AIDS threat require serious attention as do the risky health practices themselves because they help to shape public policies and impose constraints on health education programs.

Development of Self-Protective Skills and Controlling Self-Efficacy

It is not enough to convince people that they should alter risky habits. Most of them also need guidance on how to translate their concerns into efficacious actions. In the Stanford survey mentioned earlier, after exposure to the intensive educational campaign less than half of the students who were sexually active used safer sex methods designed to prevent infection with sexually transmitted diseases. Most of them even avoided talking about the matter with their sexual partners. McKusick, Horstman and Coates (1986) found that gay men were uniformly well informed about safe sex methods for protecting against AIDS infection, but those who had a low sense of efficacy that they could manage their behavior and sexual relationships were unable to act on their knowledge.

The ability to learn by social modeling provides a highly effective method for increasing human knowledge and skills. A special power of modeling is that it can simultaneously transmit knowledge and valuable skills to large numbers of people through the medium of videotape modeling. Knowledge of modeling processes identifies a number of factors that can be used to enhance the instructive power of modeling. Applications of modeling principles to AIDS prevention would focus on how to manage interpersonal situations and one's own behavior in ways that afford protection against infection with the AIDS virus. Both self-regulatory and risk-reduction strategies for dealing with a variety of situations would be modeled to convey general guides that can be applied and adjusted to fit changing circumstances.

It will be recalled from an earlier discussion that human competency requires not only skills but also self-belief in one's capability to use those skills well. Indeed, results of numerous studies of diverse health habits and physical dysfunctions reveal that the impact of different methods of influence on health behavior is partly mediated through their effects on perceived self-efficacy (Bandura, 1987a). The stronger the self-efficacy beliefs they instill, the more likely are people to enlist and sustain the effort needed to change habits detrimental to health. Modeling influences should, therefore, be designed to build self-assurance as well as to convey rules for how to deal effectively with troublesome situations. The influence of modeling on beliefs about one's capabilities relies on comparison with others. People judge their own capabilities, in part, from how well those whom they regard as similar to themselves exercise control over situations. People develop stronger belief in their capabilities and more readily adopt modeled ways if they see models similar to themselves solve problems successfully with the modeled strategies, then if they see the models as very different from themselves (Bandura, 1986). To increase the impact of modeling, the characteristics of models such as their age, sex, and status, the type of problems with which they cope, and the situation in which they apply their skills, should be made to appear similar to the people's own circumstances.

Enhancement of Social Proficiency and Resiliency of Self-Efficacy

Proficiency requires extensive practice and this is no less true of managing the interpersonal aspects of sexuality. After people gain knowledge of new skills and social strategies, they need guidance and opportunities to perfect these skills. Initially, people practice in simulated situations where they need not fear making mistakes or appearing inadequate. This is best achieved by role-playing in which they practice handling the types of situations they have to manage in their social environment. They receive informative feedback on how they are doing and the corrective changes that need to be made. The simulated practice is continued until the skills are preformed proficiently and spontaneously.

Not all the benefits of guided practice are due to skill improvement. Some of the gains result from raising people's beliefs in their capabilities. Experiences in exercising control over social situations serve as self-efficacy builders. This is an important aspect of self-directed change because if people are not fully convinced of their personal efficacy they undermine their efforts in situations that tax capabilities and readily abandon the skills they have been taught when they fail to get quick results or suffer reverses. The important matter is not that difficulties rouse self-doubts, which is a natural immediate reaction, but rather the degree and speed of recovery from setbacks. It is resiliency in perceived self-efficacy that counts in maintenance of changes in health habits. The higher the perceived self-efficacy, the greater is the success in maintenance of health-promoting behavior (Bandura, 1987a).

The influential role played by perceived self-efficacy in the management of sexual activities is documented in studies of contraceptive use by teenage women at high risk because they often engage in unprotected intercourse (Levinson, 1982). Perceived self-efficacy in managing sexual relationships is associated with more effective use of contraceptives. The significant relationship remains when controls are applied for demographic factors, knowledge and sexual experience.

Gilchrist and Schinke (1983) applied the main features of the three-component model of personal change to teach teenagers how to exercise self-protective control over sexual situations. They received essential factual information about high-risk sexual behavior and self-protective measures. They were taught through modeling how to communicate frankly about sexual matters and contraceptives, how to deal with conflicts regarding sexual activities, and how to resist unwanted sexual advances. They practiced applying these social skills by role playing in simulated situations and received instructive feedback. The program significantly enhanced perceived self-efficacy and skill in managing sexuality.

Combining factual information about health risks with risk-reduction efficacy produces good results. Because people learn and perfect effective ways of behaving under lifelike conditions, problems of transferring the new skills to everyday life are reduced. The mastery modeling approach is readily adaptable in audio or videocassette format to self-protective behavior with regard to AIDS. Large-scale applications of self-instructional programs sacrifice the guided role-playing component. However, instruction in imaginal rehearsal, in which people mentally practice dealing with prototypic troublesome situations, boosts perceived self-efficacy and improves actual performance (Bandura, 1986; Kazdin, 1978). The self-instructional approach, designed in a format suitable for mass distribution, has been shown to achieve some success in changing other refractory health-impairing behavior (Sallis et al., 1986).

Because of the high level of unprotected sexual activity and experimentation with drugs by teenagers, they are vulnerable to becoming the new high-risk group as transmitters of the AIDS virus (Mantell & Schinke, 1988). Training materials need to be developed to assist parents and teachers on how to educate youngsters about AIDS. The mastery modeling program developed by Gilchrist and Schinke (1983) provides a good prototype for application in schools. However, other channels of dissemination must be created to reach teenagers because of factional opposition to educational efforts in the schools that address self-protective behavior in an explicitly informative manner. A major segment of the teenage population can be reached by making informative audio tapes and videocassettes readily available in the settings they frequent, such as record and video stores.

Social Supports for Personal Change

People effect self-directed change when they understand how personal habits threaten their well-being, are taught how to modify them, and have the self-belief in their personal capabilities to enlist the necessary effort and resources to exercise control. However, personal change occurs within a network of social influences. Depending on their nature, social factors can aid, retard, or undermine efforts at personal change. This is especially true in the case of sexual and drug practices.

People who are fully informed on the modes of HIV transmission and effective self-protective methods are given the virus only if they allow it to happen. They often allow it to happen because interpersonal, sociocultural, religious, and economic factors operate as constraints on self-protective behavior. Some of those most at risk must contend with sociocultural obstacles to the use of prophylactic methods that afford protection against HIV infection. The major burden for self-protection against sexually transmitted diseases usually falls on women. Unlike protection against pregnancy, where women can exercise independent control, use of condoms requires them to exercise control over the behavior of men. Those who possess coercive power over their partners resist the use of condoms if it reduces their sexual pleasure, threatens their sense of manliness and authority, and carries the scary implication that they may be carriers of disease. It is difficult for women to press the issue in the face of emotional and economic dependence, coercive threat, and subcultural prescription of compliant roles for them. Women who are enmeshed in relationships of imbalanced power, need to be taught how to negotiate protected sex nonconfrontationally. At the broader societal level, attitudes must be altered to increase men's sense of responsibility for the consequences of their sexuality.

Social influences rooted in indigenous sources generally have greater impact and sustaining power than those applied by outsiders for a limited time. A major benefit of community-mediated programs is that they can mobilize the power of formal and informal networks of influence for transmitting knowledge and cultivating beneficial patterns of behavior. There are several ways in which a community-mediated approach is a potentially powerful vehicle for promoting both personal and social change. It provides an effective means for creating the motivational preconditions of change, for modeling requisite skills, and for enlisting natural social incentives for adopting and maintaining beneficial habits. Generic principles of effective programs are readily adaptable at the subcommunity level to sociocultural differences in the populations being served. In the social diffusion of new behavior patterns, indigenous adopters usually serve as more influential examplars and persuaders than do outsiders. Moreover, behavioral practices that create widespread health problems require group solutions that are best achieved through community-mediated efforts.

In their pioneering health-promoting programs, Farquhar and Maccoby have drawn heavily on existing community networks for transmitting knowledge and cultivating beneficial patterns of health behavior (Farquhar, Maccoby, & Solomon, 1984). This work provides a model of how to mobilize community resources to disseminate health information and to convey explicit guides on how to change refractory health habits. A program of self-directed change should be applied in ways designed to create self-sustaining structures within the community for promoting behavioral practices conducive to health. Persons in the community, who serve as local organizers, are taught how to design, coordinate, and implement the programs. By teaching communities how to take charge of their own change, self-directedness is fostered at the community level as well as at the personal level.

Physiological Effects of Perceived Coping Self-Efficacy

The discussion thus far has been concerned mainly with how social and self-regulatory efficacy contribute to self-protective behavior. Viewed from the biopsychosocial perspective (Engle, 1977), psychosocial factors can activate a wide range of physiological processes that can affect immune function. Stress reactions, which arise when environmental demands exceed perceived coping capabilities, are accorded an especially important role in the development of physical disorders. Perceived self-efficacy in coping with potential stressors is, of course, central to human stress.

Social cognitive theory conceptualizes stress reactions in terms of perceived self-inefficacy to exercise control over potentially aversive situations (Bandura, 1986). If people believe they can deal effectively with potential environmental stressors they are not perturbed by them. But if they believe they cannot control aversive circumstances they distress themselves and impair their level of functioning. Studies examining the microrelation of perceived self-efficacy to stress reactions show that people display little stress while coping with potential stressors for which they judge themselves fully efficacious. But as they cope with stressors for which they distrust their coping efficacy, their subjective distress mounts, their heart rate accelerates, their blood pressure rises, and they display elevated catecholamine secretion. After their perceived coping self-efficacy is fully strengthened, they manage the same stressors without experiencing any stress or elevated physiological activation (Bandura, 1987a; Bandura, Taylor, Williams, Mefford, & Barchas, 1985). Perceived self-inefficacy in exercising control over stressors also activates endogenous opioid systems (Bandura, Cioffi, Taylor, & Brouillard, 1987). There is evidence that some of the immunosuppressive effects of inefficacy in controlling stressors, such as reduced natural killer cell cytotoxicity, are mediated by release of endogenous opioids (Shavit & Martin, 1987). When opioid mechanisms are blocked by naloxone, the stress of coping inefficacy loses its immunosuppressive capabilities. Because physiological systems are highly interdependent, the types of physiological reactions that have been shown to accompany perceived coping inefficacy are involved in the regulation of immune systems. Considering that coping inefficacy activates diverse affective states and physiological reactions, it could affect immunocompetence through different pathways.

Pathways of Influence of Perceived Self-Efficacy on Immunocompetence

There are three pathways by which perceived coping self-efficacy can affect immunocompetence. The mediating processes linking perceived efficacy to immune function are addressed briefly in the sections that follow.

Stress Mediation. There is a growing body of evidence that the ability to exercise control over potential stressors can have significant impact on the cellular components of the immune system. Exposure to intermittent stressors without controlling efficacy causes impairment in various facets of immune function such as suppressed production of helper T-cells to mitogen stimulation and weaker natural killer cell activity and enhanced tumor growth (Maier, Laudenslager, & Ryan, 1985; Shavit & Martin, 1987). In contrast, exposure to the same stressful events with controlling efficacy has no adverse effects on immune function. These findings, which are based on experimentation with animals involving uncontrollable physical stressors, are quite reproducible, although they vary somewhat depending on the intensity, intermittency and chronicity of the stressors.

The adverse immunologic effects of inefficacious coping have been corroborated in correlational and quasi-experimental investigations with humans relating occurrences of life stressors to impairment of immune function and disease (Kiecolt-Glaser & Glaser, 1987; Jemmott & Locke, 1984). Exposure to acute stressors is accompanied by a reduced percentage of helper T-lymphocytes, decreased proliferative response of T-lymphocytes to mitogen stimulation, reduced natural killer cell activity, weaker immunological control over latent herpesviruses, depressed interferon production, and poorer DNA repair in lymphocytes to X-irradiation. Prolonged impairment of cellular immune function may thus increase the risk of infection and malignant disease. Although the stress of coping inefficacy is immunosuppressive, there is suggestive evidence that increased efficacy in managing stress may be immunoenhancing, at least for some immunologic functions (Kiecolt-Glaser et al., 1985; 1986). Whether the magnitude of the immunologic changes is sufficient to have significant health consequences remains to be determined.

Infectious and chronic diseases are usually the product of interacting sets of determinants. It is, therefore, unlikely that HIV infection produces AIDS independently of any other factors. Infection is a necessary but probably not a sufficient condition for the occurrence of the disorder. Among the many other factors that can alter immune function, coping inefficacy may operate as a contributing factor in several ways. Because of its immunosuppressive effects, coping inefficacy that produces chronically elevated stress may increase susceptibility to infection from exposure to the HIV virus. That some people are better able than others to fight off local invasion by the virus is suggested by instances of individuals who have an ongoing sexual relationship with an infected partner but do not become infected.

The evidence reviewed above regarding immunoregulatory interactions, suggests that perceived coping inefficacy may further impair the already damaged immune system of persons infected with the HIV virus and thus exacerbate the disorder. Apart from the common environmental stressors with which people must cope, knowledge that one has contracted the AIDS virus and the accompanying stigmatization and major social repercussions create new sources of stress and despondency. Ineffectual cognitive and behavioral coping with knowledge of seropositivity and AIDS-related problems is associated with heightened stress and depression (Namir, Wolcott, Fawzy, & Alumbaugh, 1987). Although the likelihood that infection will result in AIDS is still unknown, there is considerable variability in the rate of progression of illness from the asymptomatic carrier stage, to the lymphadenopathy stage of swelled lymph nodes, to the final stage of opportunistic infections and cancers as the ability of the immune system to fight infectious agents is severely impaired. Coping inefficacy may well account for some of this variance.

Depression Mediation. Another possible path of influence of coping inefficacy on immunocompetence is through the mediating effects of depression. Perceived self-inefficacy to fulfill desired goals that affect evaluation of self-worth and to secure things that bring satisfaction to one's life create depression (Bandura, 1987b; Holahan & Holahan, 1987; 1988; Kanfer & Zeiss, 1983). When the perceived self-inefficacy involves social relationships, it can induce depression both directly and indirectly by curtailing the cultivation of interpersonal relationships that can provide satisfactions and buffer the effects of chronic daily stressors (Holahan & Holahan, 1987). A sense of inefficacy in coping with the demands of everyday life also contributes to depression (Cutrona & Troutman, 1986; Devins, et al., 1982). There is evidence to indicate that depression can produce immunosuppression (Coe & Levine, 1987; Kiecolt-Glaser & Glaser, 1987). In a study of rheumatoid arthritis, O'Leary (1985b) reports findings that are in accord with the postulated dual linkage. Perceived self-inefficacy was accompanied by high levels of stress and depression, each of which was, in turn, associated with lowered functioning of several facets of the immune system.

Central Modulation. A third possible path of influence is through central expectancy modulation of immunologic reactivity. If physiological reactions are often activated in the presence of certain environmental cues, then those cues alone can acquire the capacity to activate the physiological reactions through expectancy learning. Ader and Cohen (1981) have shown in animal experimentation that immune function is similarly influenceable by expectancy learning. Thus, after a neutral environmental cue had been paired with a pharmacologic agent that delays the development of an autoimmune disease, the occurrence of the cue retarded the onset of the disease and lengthened the survival period.

In studies with humans, induced expectations have been shown to affect physical reactions to allergens and antigens (Fry, Mason, & Pearson, 1964; Smith & McDaniel, 1983). Experiences involving successful or failed efforts to manage environmental demands produce cognitive changes in beliefs about personal coping efficacy that have significant physiological consequences in the absence of the environmental stressor (Bandura, Cioffi, Taylor, & Brouillard, 1987). Thereafter, mere self-appraisal of efficacy to cope with the stressor lowers autonomic reactions in those whose perceived self-efficacy had been enhanced but heightens such reactions in those whose sense of coping efficacy was diminished. Such findings raise the possibility that, depending on their nature, situationally aroused self-expectations of coping efficacy may produce anticipatory immunosuppressive or immunoenhancing effects.

Research into the impact of coping inefficacy on immunological vulnerability to infection and on the onset and course of the disease in infected individuals may help to clarify some puzzling aspects of this devastating disorder. Confirmatory results would also carry implications for the development of psychosocial interventions that might offer some help for immunodeficient conditions.

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HOW IS HIV EDUCATION SIMILAR TO OTHER PATIENT EDUCATION

- Patient-centered
- Complex, multi-system problem
- Must address stages of death and dying
- Self-care and wellness (health promotion) are important
- Addresses lifelong behavior change issues
- Issues of fear and vulnerability
- Follow-up/along is important to anticipate and deal with lapses and relapse
- Disruption of personal and family relationships and role functions
- Loss of income, insurance benefits, status, access to care

HOW HIV EDUCATION IS DIFFERENT FROM OTHER PATIENT EDUCATION

- Singular significance of confidentiality stemming from social stigma
- Denial, anxiety
- HIV infection is currently incurable and irreversible
- Sensitive and problematic intervention required to address sexual, reproductive, and addictive behaviors
- Public policy formation complicated due to varying social values
- Sex and drug behaviors are private and personal decision - making activities
- Burdens of disfigurement through wasting syndrome of KS lesions; physical disability, dependence, dementia
- Possibility of passing on HIV infection in course of one's intimate relationships or to caregivers
- Extreme uncertainty characterizes entire process from exposure to infection to illness; high morbidity and mortality
- Potential exposure extends back as long as a decade
- Public fear and prejudice, i.e., homophobia, racism, sexism
- Possible abandonment and forced isolation
- Legal and ethical dilemmas

DOOR OPENING TECHNIQUES

I. Setting the Stage

- "Many people are concerned about AIDS affecting their own personal health."
  - How concerned are you?
  - Why aren't you concerned?
  - What is the nature of your concern?

- "Every American with a mailing address received the brochure, 'Understanding AIDS'."
  - Are you familiar with this brochure?
    - How has AIDS affected your life or lives of your friends?

II. History-Taking

- "Because of the increase of AIDS it's important for you to know whether or not you're at risk."
  - Are you currently in a relationship and sexually active? What activities?
  - When you engage in sexual activity (make love) is it with men, women, or both?
  - Do you have a steady sexual partner? (monogamous/ married)
  - Have you had more than one sex partner in the past year?
  - Are you aware of your partner's HIV status?
  - When you make love, do you prefer men or women, or both?

III. Risk Assessment

- Can you share the kinds of sex practices in which you engage?

- Do you use street drugs?
  - How do you use them?

- Are you currently sexually active with more than one partner?

IV. Safe Sex

- What kind of protection do you or your partners use during sexual activity?

Motivating Patients to Use Condoms

• • •

By Edward E. Bartlett, Ph.D.

Condom counseling is an essential skill for health professionals involved in HIV care. The Surgeon General's Report concluded that with appropriate education and information, 12,000–14,000 lives could be saved from AIDS in 1991. The only truly "safe sex" is abstinence or a mutually monogamous relationship with an HIV-negative partner. However, for those persons at high risk for HIV infection who do not wish to follow these measures, use of a condom can contribute significantly to stemming the spread of the HIV epidemic. Condoms act as a physical barrier to transmission of HIV and an appropriate spermicide can also kill the virus.

Condoms are appropriate to both male homosexual and heterosexual intimate contact. While they are less protective for anal intercourse than for vaginal intercourse, some protection is better than none. Condoms should be used whether *both, either, or neither* (but there is uncertainty of that fact) of the partners has the HIV virus. Discussing condom use is appropriate at all points in the spectrum of HIV infection: primary prevention, before and after HIV testing, and for patients who are seropositive, have ARC, or have AIDS.

When it comes to counseling about condom use, health professionals fall into one of two categories: the avoiders and the inundators. The avoiders are squeamish about taking a detailed sexual history and make a hurried allusion to "avoiding body fluids." The inundators go to the opposite extreme. Operating under the premise that "more is better," they launch into their standard speech on the need for and techniques of condom use. I recall an enthusiastic counselor who saw a woman whose husband was an IV drug user. Only after he delivered his routine 10-minute condom discourse did he realize that she was sexually abstinent.

The problem for the avoiders is they just do not know where to start. The problem for the inundators is their approach is very inefficient, and often ineffective. Use of the behavioral diagnosis technique can solve both counseling problems.

It is almost trite to say that the premise of effective medical care is that diagnosis precedes treatment. So it seems odd that when it comes to counseling, we omit the diagnostic step, and select our educational "treatments" based only on *a priori* assumptions of what the patient needs.

What is a "Behavioral Diagnosis"?

Behavioral diagnosis is the process of identifying the obstacles to making the desired behavior change. These include knowledge deficits, misconceptions, fears, lack of skills, lack of social support, or inadequate resources to purchase the product. Sometimes these obstacles seem ridiculous or unjustified to the AIDS counselor. *Yet experience shows that taking these obstacles seriously and trying to address them often spells the difference between success and failure in achieving behavior change.*

Experience with condom counseling to reduce transmission of the HIV virus reveals 18 common obstacles and objections to condom use, including such problems as embarrassment in purchasing condoms, believing that one can "pick out" persons who are virus-free, and fear of reduced sensation and condom breakage. These obstacles will vary with the client's cultural and racial background. Hispanic patients, for example, often associate condoms with prostitution. Attempting to cover all 18 concerns may take from 30 to 60 minutes, and is inappropriate because a given person typically has only two to five concerns. Therefore, the key to effective and efficient counseling is to first do a behavioral diagnosis.

How Do You Do a Behavioral Diagnosis?

You can easily make a behavioral diagnosis by asking open-ended questions such as: "Have you used condoms be

> "When it comes to counseling about condom use, health professionals fall into one of two categories: the avoiders and the inundators."

Behavioral Diagnosis for Condom Use

Obstacles/Objections to Using Condoms	Educational Strategies
Cannot afford	Condoms can be purchased for as little as 30¢ each, or even obtained free.
Embarrassing to purchase condoms	Pharmacies do not think twice about selling condoms; condoms also can be purchased by mail.
Forgot	Develop the habit of using a condom *every time*, so it becomes second nature.
Implies I do not love or trust my partner	Love means you are truly concerned about your partner's—and your—desire to remain healthy. Try a humorous—and firm—approach of offering a variety of condoms to your partner to choose from.
I know my partner does not have the virus	You may be kidding yourself—just because your partner shows you proof that he/she is HIV-negative does not mean that he did not contract the virus *after* the test. Assume that *everyone* is a potential carrier of the HIV virus.
My partner does not have AIDS—so I can't get the virus	Most people with the virus do not have any symptoms of AIDS. Any person with the virus can pass it on to others.
Using a condom means I carry the HIV virus	No—many persons who use condoms do not carry the HIV virus, thanks to the fact that they use condoms.
Not easily accessible during lovemaking	Keep extra condoms at bedside and at other places for lovemaking.
Distracts from lovemaking	Take out of foil before lovemaking; incorporate condom into foreplay; use specially scented condoms.
Penis is too big	A condom can be expanded to go around your fist. Condoms usually break because of poor lubrication.
Reduces sensation	Place dab of lubricant *inside* condom at head of penis; use of condom *prolongs* the sexual experience; use ultrathin condoms; gently roll condom on to eliminate air bubbles.
Lubricant gets dry, causes irritation	Use other water-based lubricant; use water to reactivate lubricant; place lubricant on vaginal/anal opening.
Water lubricant distasteful for oral sex	Purchase condoms without lubricant.
Condom slips off	Do not place lubricant directly on penis shaft; hold condom with hand at base of penis.
Condom breaks	Use water-based lubricant; use condoms with receptacle end; do not store in warm area (such as hip wallet).
Associated with prostitutes	The overwhelming number of condoms are not used by prostitutes.
Associated with low-income persons	Condoms are as much part of the "lifestyles of the rich and famous" as any other g
Forget to use when drunk or high	Reduce or eliminate alcohol or drug intake.

fore? . . . What problems did you have?" "What do you think will be the most difficult about using condoms on a consistent basis?"

Sometimes the HIV counselor will need to supplement the open-ended questions with closed questions such as: "Some of my patients feel that using a condom means you do not really trust your partner—is that one of your concerns?" "Have you ever had the condom accidentally slip off?"

Sensitivity to the clients' lovemaking preferences and perceptions also will promote an honest exchange: "I know that using condoms for oral sex is the last idea many people want to consider—is that a concern for you?"

It is important that rapport be adequately established before attempting the behavioral diagnosis. Patients will reveal their true concerns only in a supportive environment. Failure to achieve this will elicit excuses rather than the true obstacles to making difficult behavior changes.

The initial behavioral diagnosis often reveals two or three obstacles. As the caregiver addresses these, additional obstacles may become evident, and these will also need to be discussed. As the client attempts to use condoms, he or she will encounter new or unexpected problems. The behavioral diagnosis will need to be updated and revised during subsequent clinic visits.

Once the barriers to behavior change are identified, the counseling strategies are straightforward. If the person simply forgot, he or she needs to be reminded to develop the habit of always using a condom. If the client complains of reduced sensation, emphasize ways that condoms can enhance sexual pleasure. (See Table 1 list of the 18 obstacles and corresponding educational strategies.)

Behavioral Diagnosis in Practice

Hundreds of physicians, nurses, and counselors around the nation have been trained in the behavioral diagnosis technique since 1983, when it was first introduced in an article in *Patient Counseling and Health Education* (Vol. 4, 1983, pp. 29–35). The technique can be taught to a group of health professionals in a one- to two-hour presentation, which may entail a minimum of $600 in training expenses. Experience reveals that although the technique can be easily learned, its consistent application requires unlearning the caregiver's usual approach and developing a more interactive style of counseling. This may require follow-up and observation in the clinical setting.

Some caregivers perceive that doing a behavioral diagnosis will require more time. If in fact they are currently doing little or no behavioral counseling, their perception is no doubt correct. However, those who use the lecture approach are often surprised at how much time they save when they target the discussion to overcoming the actual obstacles. And use of this approach may well make the difference in remaining HIV-free for many.

Avoiding Unwarranted Assumptions

The behavioral diagnostic approach to condom counseling helps the caregiver to avoid making unwarranted assumptions. One of the most common fallacies is assuming that because the patient has led a "swinging single" lifestyle, he or she is sophisticated in sexual matters. One female patient seen at a local HIV testing clinic had had many male partners, but was completely ignorant of the reason for the condom's receptacle end. Many others continue to use VASELINE petroleum jelly or baby oil for lubrication, which can weaken the condom.

A 34-year-old man with AIDS made the following statement shortly before he died: "I have AIDS, and AIDS is not *my* problem. AIDS is *your* problem. Through better education, we can prevent a single additional person from getting the AIDS virus." Following the approach described here will be one of the most important steps the health professional can take to meet this challenge. ☐

How To Advise Your Patients on Condom Selection and Use*

1. **Condoms should be made of latex, not lambskin. Condoms should have a reservoir tip and have the spermicide nonoxynol-9 which has been shown to kill the HIV virus. Ramses Extra® and Excita Extra® are two brands that meet these criteria.**
2. **Water-based lubrication is essential to avoid condom breakage. Lubrication should be applied to the outside of the condom *and* to the inside of the partner.**
3. **To assure the condom is correctly placed, it should be put on *after* the penis is erect but *before* either partner is extremely aroused. Be careful that long fingernails do not tear the condom.**
4. **Unroll the condom to the bottom of the penis. Holding the condom with the hand will assure the condom does not come off during exuberant intercourse. In heterosexual intercourse, this can also provide the woman with extra stimulation.**
5. **The condom should be removed before the penis is completely relaxed.**
6. **A new condom should be used for each ejaculation.**
7. **Do not store condoms in warm places such as hip pockets or glove compartments.**

*** Adapted from *Safer Sex: Guidelines for the Prevention of Transmission of the AIDS Virus*, Department of Hematology, George Washington University Medical Center, Washington, D.C.**

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STRATEGIES FOR HIV/AIDS PATIENT HEALTH EDUCATION WHEN TIME IS LIMITED

General Suggestions

Display posters to give the message that this is a place where clients can ask/talk about AIDS -- consider also hanging them in the bathrooms
Run AVs about AIDS in the waiting room
Have condoms and educational materials about AIDS in the waiting room
Make up packets (a condom, a small bottle of bleach, printed materials in a baggie) to give everyone

Five Minutes

Listen to client's concerns
Ask: Do you think any of these present a risk for you?
Or: Do you think your partner is at risk?
Ask: Do you have any questions or concerns about AIDS?
Or: Do you know how to protect yourself against AIDS?
Give the AIDS Hotline Phone Number
Give client a pamphlet to review -- with local resource for follow-up (use pamphlets with neutral covers about health so people won't be shy about picking them up, or use wallet-size or matchbook printed materials)
Make up an information sheet listing names and phone numbers of local agencies/resources along with the specific AIDS-related services they offer (also national resources with 800-numbers) to give clients
Give the most important information:
- -AIDS is spread by having sex with someone who has the virus or by drug users sharing needles and works
- -Regular and correct use of condoms will probably protect you

Ask client to say what s/he's heard so far to check out whether s/he's following you or has misperceptions -- correct as needed
Make sure you provide a resource (including yourself) for follow-up
Help client make an appointment to talk further with someone on staff or in the community
Give extra copies of materials so client can pass them on to partner, friends, family

Fifteen Minutes

Above strategies plus:
Ask if client has any questions or concerns about HIV test
Ask about risk in sexual relationships
Ask about drug use and risks around drug use
Help client assess personal risk
Help client develop strategies for negotiating safer sex
Demonstrate condom use
Give basic information about HIV test
If follow-up visit:
    -assess progress in making lifestyle changes
    -reinforce previous information
    -listen to new concerns

Thirty Minutes (Or More)

Above strategies plus:
Goal -- client will leave with a personalized plan for risk reduction
If client appears from above to be high risk, offer testing option:
    -anonymous test centers
    -confidentiality issues if tested in the VA
Discuss decision making around testing
Make referral for testing, if appropriate
Discuss feelings about AIDS
Discuss AIDS and reproduction
Have client return condom demonstration if comfortable enough
Explore ways to get client and partner acceptance of condom use, including mental rehearsal and/or role play
Refer (or schedule back) for further information and/or service, including social/peer support for implementing personal risk reduction plan

Diagnosis/Treatment/Prevention

Implications of Relapse From Safe Sex

Ron Stall, PhD, MPH and
Maria Ekstrand, PhD

The dominant approach in AIDS prevention efforts among gay and bisexual men in the United States is to encourage the adoption of safe sex practices. Among the techniques used to effect this change have been the widespread dissemination of AIDS risk reduction information, focused group interventions to demonstrate ways to eroticize safe sex, and the use of group norms and social support to motivate behavior changes. These efforts have been highly successful and have resulted in the most profound modifications of personal health-related behaviors ever recorded.[1]

For the large coastal cities in the U.S. with well-established gay male communities, the emphasis on adopting safe sex methods may be outdated. A more important focus may be the prevention of relapse to prior high-risk behaviors among those men who have adjusted their behavior. This change in emphasis would be consistent with what is known about the difficulties associated with changing other behaviors—such as smoking, alcohol use, diet and a sedentary way of life—that can result in an increased risk of death. It has long been recognized that it is often more difficult to maintain long-term sobriety from alcohol or drugs, for example, than to make the initial change to these healthy behaviors.

The importance of discouraging relapse from safe sex in heavily populated gay areas is also consistent with what is known about the prevalence rates for HIV infection in those communities: here are very high levels of risk for new HIV infection caused by ehavior relapse. Only the long-term and consistent practice of safe sex will prevent further infection within these communities.

Study Design and Findings

The AIDS Behavioral Research Project (ABRP) was originally designed to determine how the AIDS epidemic was influencing gay men's psychological adjustment and sexual risk behavior.[2,3] ABRP modified a scale developed by the Chicago Multi-Center AIDS Cohort Study and divided participants into four categories—no risk, low risk, modified high risk and high risk—depending on a combination of frequency of anal sex and condom use during sexual activity in the prior 30 days.[4]

Since the AIDS Behavioral Research cohort has been followed for over four years, it can be used to provide an estimate of long-term relapse rates among men who previously practiced only safe sex, but who reverted to high-risk sexual behaviors. As these relapse rates are based on behaviors that occurred during the previous month, they are probably lower than they would have been had they been based on all sexual behaviors that occurred over the previous year.

Of the 453 men who responded to all waves of data collection, there was a decline of 59 percent in the incidence of participation in high-risk sexual behavior between 1984 and 1987. The percentage of those in the sample who were included in the high-risk category dropped from 38.7 percent to 15.5 percent. The incidence of celibacy, which implied no sexual risk, increased from 12.6 percent to 22.5 percent of the sample over the same time period. The most common risk level in 1984 for this sample was high risk, but changed to low risk by 1985 and has stayed at this level since that time.

The study also tracked changes in behavior among individual articipants in the project. At four points in time over the study eriod, from 1984 to 1987, individual behavior was rated. From this data, four patterns of change were developed: stable low risk (not at high risk at all); changed to low risk (changed from high risk to low risk without returning to high risk); relapse (changed for at least one point in time to high risk from low risk); stable high risk (at high risk for all four points in time).

Over this four year period, 50.8 percent (230 men) were in the "stable low risk" category, 29.8 percent were in the "changed to low risk" category, 15.7 percent were in the "relapse" category and 3.8% were in the "stable high risk" category. In other words, the relapse rate is four times higher than the rate of consistent high-risk sex. Given the very high background rates of HIV infection within this community during this period, it is clear that relapses from safe sex, however occasional, constitute a threat to the health of gay men in San Francisco, and likely in other cities.

Preventing Relapse

Gay men in San Francisco and in other urban centers have reduced their risk of HIV infection in significant ways. Nonetheless, as seen in all health behavior change programs, a minority of individuals are resistant to prevention education and to reducing risk of infection. Still others have occasional high-risk sexual relapses. Both patterns of engaging in high-risk sexual activity constitute a serious risk for continued HIV infection in this population.

For the men in one representative sample, the predominant risk for further HIV transmission is related to relapses from the practice of safe sex. Whether this same situation exists outside of the large coastal gay communities remains unanswered.

> *Educators must distinguish between the motivations for initial risk reduction and those associated with the long-term maintenance of risk reduction.*

This review of study data suggests changes for future AIDS education programs. Educators must distinguish between the motivations for initial risk reduction and those associated with long-term maintenance of risk reduction. For example, it may be expected that variables such as understanding health education guidelines would be associated with initial risk reduction, while factors such as social support for low-risk sex and changing community norms would be correlated with the maintenance of low-risk behavior over time. Startegies to prevent relapse should be based on an understanding of this distinction and should be derived from predictors of maintenance rather than predicators of initial change. An analysis of these predictors is forthcoming.

To be truly effective, interventions must include the proper mix of techniques to encourage both the adoption of safe sex practices and the continued adherence to these practices. Both of these messages will be necessary, even in the large coastal gay communities, where some men continue to have unsafe sex consistently, and other men join the gay community, as new arrivals or as recently acknowledged gay men.

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THE MORIN MODEL

Suggests that a person must hold five beliefs in order to change his/her behavior in relation to AIDS, and that these beliefs can be directly influenced by educational and motivational programs, beliefs tend to occur sequentially.

1. "I am personally threatened by AIDS."
2. "AIDS is preventable; certain actions will reduce or eliminate my risk."
3. "I am capable of managing these new low-risk behaviors."
4. "I can carry out these new behaviors and still be.....satisfied."
5. "My peers will support this new behavior."

SOURCE: S.B. Puckett and L.L. Bye, "The STOP AIDS Project: An Interpersonal AIDS Prevention Program," 1987.

RELAPSE PREVENTION

Relapse prevention is a most important aspect of substance abuse treatment. If the client experiences a "slip" it is necessary to review exactly the actions which led to the "slip". If we know the actions we can prevent a repeat.

On a small file card type the following for your clients to carry around with them:

1. Treat a "slip" as an emergency situation requiring immediate action.
2. Remember that one "slip" is not a complete relapse.
3. Renew your commitment.
4. Review the actions which led to the "slip" so you won't repeat them.
5. Make an immediate plan for recovery.
6. Ask someone for help.

Shame and guilt often follow a "slip". Let it pass - it is quite natural that you have these feelings.

The above is adapted from suggestions made by Allan Marlatt and Judith Gordon in a book entitled: Relapse Prevention, Guilford Press, 1988.

Bella H. Selan

PATIENT EDUCATION ABOUT AIDS

What is AIDS?

- Caused by a virus named the Human Immunodeficiency Virus (HIV)
- Infects the body and slowly damages the immune system
- Leaves the body susceptible to certain types of pneumonia, cancer, and other infections

How is the HIV Spread?

- By unsafe, unprotected penetrative sex with someone who is infected
- By sharing dirty needles with someone who is infected
- By using untested blood products
- By infected mothers to their babies (in the womb, at birth, or breastfeeding)
- NOT by casual contact

What are the Symptoms of HIV Infection?

- Prolonged fatigue or general "unwell" feeling
- Swollen lymphnodes (at neck, under arms, or groin) longer than 3 months
- Persistent fevers or night sweats
- Explained weight loss
- Unusual red or purple skin spots that don't go away
- Thick white coating on the tongue or in back of throat
- Easy bruising or bleeding

(These symptoms can be signs of many different illnesses; check with a doctor for proper diagnosis.)

Who is at Risk of HIV Infection?

- Anyone who engages in behaviors known to spread the HIV (see above)
- Some members of certain groups of people have been most affected by HIV so far; those groups are:
    - Gay-identifying men with multiple partners
    - Men and women who use intravenous drugs - narcotics and steroids - and share their needles with others
    - Men and women employed in the sex industry
    - Youth (teenagers and young adults)
    - Sexual partners of those who are infected with the HIV
    - Sexually active adults (including men who sometimes have sex with other men)

How to Avoid Infection with the HIV?

- Abstain from risky sexual activity and IV drug use
- Use condoms, or other barriers, during oral, vaginal, or anal sex
- Reduce the number of sexual partners, especially anonymous contacts
- Avoid taking semen, vaginal secretions, or blood into your body
- Avoid sexual practices that may cause trauma to skin or mucous membranes
- Avoid needle sharing during intravenous drug use
- Clean needles and other drug paraphernalia between uses and users
- Avoid becoming pregnant until you know the HIV is not in your body

SOURCE: (This material is adapted from) G. Carr and G. Gee, "AIDS-Related Conditions: Screening for Populations at Risk," in AIDS: Concepts for Nursing Practice, edited by G. Gee and T. Moran. Williams & Wilkins Publishers, Baltimore, MD. 1988.

COMMUNICATION SCIENCE RESEARCHERS' VIEWS ON HIV/AIDS-RELATED BEHAVIOR CHANGE

The casual chain that occurs between exposure to (behavior change) messages and (actual) modification of behavior is very complex. The relationship between exposure and behavior change occurs in a series of steps:

1. Exposure will lead to Awareness, but only when the message is heeded;

2. Awareness will lead to Changes in Knowledge, but only when the message is comprehended;

3. Changes in Knowledge will lead to Changes in Beliefs, but only if the arguments or conclusions of the message are accepted;

4. Changes in Beliefs might lead to Changes in Attitudes, Intentions, and ultimately, Behavior.

INTERPERSONAL COMMUNICATION ABOUT SAFE SEX

The series of steps cited above applies to mass communication for HIV prevention as well as to interpersonal situations in which risk-reducing behaviors are actually practiced. Educational efforts will be rendered ineffective if individuals are aware of and motivated by the AIDS information to which they have been exposed through various media or interpersonal sources but experience communication difficulties in the private moments when knowledge must be put to use.

The special characteristics of the behavioral measures necessary to prevent HIV/AIDS transmission dramatically increase the need for skillful interaction. This is especially true for the practice of safe sex. Unlike many other preventive measures, safe sex cannot be practiced by one person without the knowledge and cooperation of another.

The practice of safe sex is unique. Unless one partner is completely naive to the realities of sexual intercourse, safe sex cannot be carried out unobtrusively. Especially in the case where a condom is used, both partners will be totally aware of the behavior that is transpiring. Agreement and cooperation are necessary conditions for the successful completion of appropriate behaviors.

There are many occasions in which safe sex should be practiced but cooperation does not always occur and agreement is reached. There are three important variables of interpersonal communication relating to safe sex talk, i.e., self-presentation, conflict management, and persuasion.

SELF-PRESENTATION

The need for a positive self-image is a powerful factor that can interfere with the practice of safe sex. Many individuals maintain a romantic ideal of sex that does not allow for unpleasantries. By its very nature, discussion of and request for safe sex is an implicit disclosure of fear and anxiety about HIV infection and AIDS. Such discussion or request may expose one's negative self and increase the possibility of rejection by one's partner. Asking someone to take preventive measures tacitly indicates a suspicion that one's partner is infected with HIV. If an individual is very sensitive about creating a positive impression, then he or she is likely to avoid the communication of any messages that might call into question the partner's character or behavior. People must realize that disclosure of negative feelings and fears is a risky proposition but that such action can have positive consequences.

CONFLICT MANAGEMENT

A request to practice safe sex may not necessarily be granted; thus producing a possibility for conflict. A situation arises wherein one person seeks to modify the behavior of the other against her or his wishes. In a situation where safe sex should be practiced and is requested, the most dysfunctional response to conflict is avoidance. With this response, conflict has in one sense been resolved, but not in a manner that is ultimately favorable to either person. This type of conflict often occurs in relationships that are more casual.

Conflict also may be avoided because one partner feels a lack of power to negotiate successfully. This may result from adherence to a sex role stereotype. Some women may accept the myth that men have the prerogative to control a sexual encounter and act as sexual experts. This perception inhibits individuals from exercising proactive power, which allows one the freedom to initiate expressions of sexual desire and maintain sexual autonomy. The more positive communication is likely to transpire only when both partners have high self-esteem and feel comfortable with their own bodies and sexuality.

PERSUASION

A person who asks his or her partner to practice safe sex and is refused has the option of vetoing the sexual encounter. In this scenario, the risk of HIV infection has been eliminated, but both partners have been denied sexual pleasure. A more gratifying alternative would be for the person who desires safe sex to use persuasive strategies to convince the reluctant partner to change her or his attitude. Choosing the best available means of persuasion is tricky in any context, but the task is especially complex when the encounter involves two people who have had little experience in interacting with one another.

Despite the obstacles, the chance for effective communication is high if basic principles of interpersonal persuasion are followed. One of the most important is that the persuader must consider the reasons why his or her partner is reluctant to practice safe behaviors, i.e., why has resistance occurred.

Once the persuader understands the basis for non-compliance, she or he may attempt to influence behavior by reframing the situation for the partner. For example, he or she might try to portray condom use as a positive, sensual experience rather than as a necessary disease prevention measure.

SOURCE: "The Role of the Mass Media and Interpersonal Communication in Promoting AIDS-Related Behavioral Change," by Timothy Edgar, Sharon Lee Hammond, and Vicki S. Freimuth. Published in AIDS and Public Policy Journal, Volume 4, No. 1. 1989.

The Crisis of Communicating in Relationships: Confronting the Threat of AIDS

Sheryl Perlmutter Bowen and Paula Michal-Johnson

It is no secret that AIDS puts a strain on modern relationships. People face choices in their intimate relationships that may have more serious consequences than ever before. It is not well understood whether the increased awareness of AIDS fostered by the media and educational campaigns has changed the way people relate in their intimate relationships. Have young adults made changes in the ways they conduct intimate relationships? Are they aware of a need to address issues related to AIDS in their conversations with one another? What criteria are being used to determine whether a potential intimate partner is infected with the human immunodeficiency virus (HIV)? These and other questions triggered a pilot investigation of talk about AIDS in romantic relationships among heterosexual college students.[1,2]

As communication researchers we would like to believe that talking can work to reduce the transmission of HIV. Theoretically, interpersonal interaction provides information for self-assessing the risks associated with specific sexual and social behaviors. Such information could promote the choice to negotiate safer intimacy with sexual partners. The goal of this essay is to describe how the college students we studied construct the meaning of the AIDS crisis. In this paper, we 1) describe the assumptions that can be made concerning the role of talk about sensitive relationship issues among intimates; 2) describe how college students talk about AIDS in romantic relationships; 3) present the reasons they give for not talking about AIDS in their relationships; and 4) identify alternative information-gathering and decision-making strategies used by the college students we studied. In the latter part of the paper we examine the implications of these findings for public policy. A primary goal of this paper is to determine whether the theoretical assumptions about relationship talk described in item 1 above are supported by students' own accounts of their talk about AIDS.

Study Design

To gather demographic and relationship experience information, 147 males and 96 females, students in public speaking classes at a mid-sized eastern university, were asked to complete a confidential, self-administered questionnaire. This instrument was used to determine respondents' demographic characteristics, number of dating and serious relationships since high school, current relationship status, level of sexual activity, and self-rating of knowledge about AIDS. In addition, the 243 students were asked to respond to three open-ended questions: 1) Have you ever talked about AIDS with a partner? 2) Have you ever wanted to talk about AIDS with a partner but did not? What kept you from doing so? 3) Have you ever gathered information about a (potential) partner indirectly, that is, other than by asking for specific AIDS-related information? Respondents were asked to elaborate on their answers and to describe actual episodes when possible. Chi-square analyses were conducted to discover significant relationships between demographic and relational behavior variables and communication strategies.

The responses to the open-ended questions were content analyzed utilizing an inductively obtained coding scheme that placed every segment from a response into some category, whether it was an episode marker or a specific behavior. Originally, data from each of the three open-ended questions were analyzed separately. However, answers for reported talk about AIDS and indirect strategies used to get information about partners had overlapped considerably. In this report, strategies culled from the two sets of responses are reported as they fit into one of two broad and distinct areas: strategies that explicitly require partners to communicate (called *talking*) and those that do not necessarily demand talk between partners (called *indirect*).

Underlying Assumptions About the Nature of Talk in Relationships

In attempting to understand the nature of communication about AIDS, we take a constitutive perspective, that communication occurring in the relational context creates relationships.[3,4] Talk, through the use of symbols, names and defines relationships; it creates the worlds in which relationships are transacted.[5-7] Analysis from such a perspective examines how talk can produce outcomes such as intimacy, conflict, satisfaction, interpersonal attraction, or trust. Two specific outcomes are relevant to our concern with AIDS: relationship satisfaction and protection against high-risk behaviors. We suggest that attention to communication skills is one way to help individuals to deal effectively with AIDS in their relationships.

> *“The immediate threat to the relationship might discourage talk about a potential health crisis, the impact of which will not be detectable for some time.”*

Levels of Talk

Katriel and Philipsen describe a cultural phenomenon that differentiates “mere talk” from “real communication.”[7] This distinction points to the difference in how the theorist and the naive social actor conceptualize communications. In the Katriel and Philipsen investigation, “chitchat,” or superficial exchanges, are considered “mere talk.” Included in this category are most interactions with people in service capacities (restaurants or stores), as well as any interaction with known others that is tightly governed by rules of acceptability. Such interactions are often rigid, neutral, and distant, whereas “real communication” is flexible, supportive, and close. Typically, the quality of interaction shifts as a couple continues to develop their relationship.[9,10] Certainly, not all interactions in any given relationship are real communication; much communication may be “small talk.” In either case, both types of talk serve functions in relationships. Small talk provides the social cement that holds relationships together. It enables people to carry out the seemingly mundane activities that account for huge portions of their lives, such as deciding which movie to see or how busy work schedules can be manipulated to allow time together. These routine interactions allow the partners to see that the roles previously negotiated still hold and that the status of the relationship has not changed. Real communication, on the other hand, is likely to be specifically about one's “self” or “the relationship.” This is usually purposive and direct talk about a particular issue, but it may arise spontaneously.

Communication Skills

When we began our study, we imagined that talk about AIDS would be real communication, specifically addressing an issue germane to each partner and to the relationship itself. At some point in a couple's normal interactions, we suspected that one partner would initiate discussion about AIDS. Examining national campaigns for safer sex, we wondered how partners actually negotiate safe sex. Based on what we know about effective interpersonal communication, we realized that some amount of skill would be required. Partners would need more than minimal skills to introduce the topic, gather and share information, disclose feelings, and negotiate roles and behaviors.[10] In addition, each partner would have to be sensitive to the implicit rules regarding the timing of particular disclosures in relationships. Introducing a topic too soon might signal a change in the trajectory of the relationship, possibly triggering its dissolution.[3] Avoiding the issue, superficially introducing it, or failing to be assertive might be tempting because the partners are likely to be more concerned with maintaining their relationship than with effectively confronting the AIDS issue. The immediate threat to the relationship might discourage talk about a potential health crisis, the impact of which will not be detectable for some time. Even given that AIDS is perceived differently than other sexually transmitted diseases,[11] talk about AIDS, when it does occur, would be most likely to happen in situations that would not jeopardize relationships.

Speculation based on understandings of relationship communication suggests that AIDS may be introduced for discussion when one partner needs information about the other in order to estimate risk, when the partners discuss general concerns about AIDS, or when one partner is personally fearful.[12] The subject may come up either in the context of an initial encounter or in an ongoing relationship. AIDS may also become an issue when a couple negotiates the sexual aspects of their relationship. On the other hand, it is possible that students avoid talking about these issues altogether.

Taboo Topics

Given the wide dissemination of AIDS messages in the media and the school setting, one would expect that individuals would talk about the issue as a way of taking responsibility for their own health and safety, not to mention the safety of their relationships. Most people are aware that they should be talking about these issues, but for many reasons they choose not to do so. Several studies have indicated that college students typically refrain from discussing issues that might be perceived as necessary to the continued development of relationships.

Baxter and Wilmot[13] identified six primary types of "off-limits" subjects in reports of taboo topics in college students' relationships: 1) the state of the relationship, 2) extra-relationship activity, 3) relationship norms, 4) prior relationships with opposite-sex parties, 5) conflict-inducing topics, and 6) negatively valenced self-disclosures. It is not surprising that the topics that render partners the most vulnerable to hurt or violation of trust are those that people report avoiding.

These six taboo topic areas would lead us to believe that talk about AIDS in relationships is limited. For instance, the following topics would be avoided: information about the past that might be useful in assessing risk, any talk about the current relationship (e.g., explicit negotiation of appropriate behaviors), and discussion about activities outside the relationship (e.g., drug use or sexual behaviors). These are, undoubtedly, difficult issues for even the most communicatively skilled partners.

Tests to Gain Information About Relationships

Additional evidence suggests that relationship partners may not directly ask for or receive sensitive information about the state of the relationship. In a previous study, Baxter and Wilmot[14] investigated how subjects got delicate information about their relationships. They found that the college students in their sample tested the loyalty or jealousy of a partner with secret tests. For instance, one subject asked her partner to drive an hour out of his way to pick her up. His doing so was evidence that he cared for her. An alternative indirect strategy for gathering information entailed asking a third person about the partner. This empirical evidence suggests that some sensitive relationship issues are likely to go unexamined and, furthermore, that individuals construct strategies for testing their partners. We suspected then that the college students in the AIDS study would yield to these tendencies. We must be reminded that there are some difficulties in advocating direct discussion of AIDS if people do not regularly confront other issues in their relationships. Communication researchers may have to confront their own bias that talk will enhance most relationship situations.

Reports of Talk About AIDS

The estimates of talking about AIDS in intimate relationships vary. Chervin and Martinez,[15] in their study of college students at Stanford, reported that 24 percent of their sample discussed AIDS prior to sexual intimacy. However, it is not clear how they talked or whether the talk was superficial or serious and involved. Generic talk about AIDS in relationships was reported significantly more often in the study described here.

In our study, 56 percent (N = 138) of all respondents reported talking about AIDS in a relationship. Proportionately more women than men reported talking (64.6 percent compared with 52.4 percent of men, chi-square = 3.49, df = 1, P = 0.06). Specifically, women who had had intercourse were more likely to report talking about AIDS with their partners (chi-square = 3.69, df = 1, P = 0.05). Not surprisingly, the vast majority of respondents talked in ways that did not challenge their relationships, although more than half indicated that, in general, AIDS has changed the way they date.

Many of the respondents said something to the effect that "we talk generally" and did not elaborate. Many others provided expanded answers to the question. The six most commonly described AIDS talk strategies were

1) directly asking the partner about his or her past relationships and behavior;
2) strategically gathering information about the other;
3) making judgments about the safety of oneself and/or one's partner;
4) explicitly negotiating the current relationship;
5) estimating specific risks; and
6) generally talking about AIDS as a public issue.

After an overall description of the reported talk about AIDS, we will offer excerpts from the data and suggest how each strategy functions in the relationship context.

The vast majority of comments about AIDS were made casually. Talk was described as general or casual or as brief mentions or asides. Even for those who described their AIDS talk as open or direct, the length or detail of the interaction is questionable. Often AIDS-related comments were stimulated by a television program or commercial (or some other media item, in newspapers, magazines, or on the radio). AIDS seems to be a topic that is mentioned when a couple is alone. It is also one that promotes a great deal of joking behavior.

Using the media, a joke, or a conversation about other people known to the partners was reported fairly often as a way to initiate talk about AIDS. However, this talk was often small talk, not in-depth conversation about AIDS and its direct link to the partners and their behavioral choices. These strategies do not necessarily protect individuals from HIV transmission. If a comment is made jokingly, there is no indication that, as a result, safe sex practices will be followed. Joking and similar techniques are safe ways to talk about AIDS in relationships, some level of misinformation was apparent. One participant said, "I assume girls protect themselves"; another said, "She's on the pill so condoms are unnecessary." These are from only two of the many research participants, but their responses are frightening in their implications for the extent of knowledge about AIDS virus transmission in this population. Finally, this strategy affirms the relationship for the person who uses it--if we're safe, then we can stay together and do what we want. A rationalization or justification to the self for continuing a relationship seems to be operative here.

Negotiating the Current Relationship

Partners used AIDS as a reason for negotiating various aspects of their relationships. For instance, some established rules for behavior with other people (e.g., "setting rules for boyfriend at other school about dating others"). Other people used AIDS as a way of expressing trust in each other or as a reason for committing to one another, possibly agreeing to a monogamous relationship (e.g., "It's a way of expressing our commitment to each other--not seeing other people"; "we agreed how hard it would be to find new partners"). A few respondents used AIDS as a "threat against breaking up"--if the couple were to break up, surely one would get AIDS because he or she presumably would sleep with someone at high risk. Given that the partners know that each is not infected, staying together is insurance against becoming infected. Using this strategy, couples addressed the relationship explicitly. Somehow, they had to agree on the terms for continuing the relationship.

Estimating Specific Risk Factors

A number of students discussed HIV test results, transfusions, sexually transmitted diseases, or general risks with their partners. This strategy reflects direct confrontation of the issue, but it was reported as a factual piece of information, not as a reflection of serious fears or concerns. Several in our sample were involved in (or with someone who was in) a military ROTC program in which testing was routine, and they treated the information in a similar fashion. Others indirectly indicated their knowledge about AIDS by reporting discussions of "how to avoid" certain risks. Treated as an objective fact, discussions of specific risks are not particularly threatening to the relationship, provided they reveal antibody-negative status.

There is some evidence, although not overwhelming, of behavioral change that may be a result of AIDS awareness. Two women ended relationships because they discovered aspects of their partners' histories and deemed them risky. Some men reported that they might not go out with a woman if she had a "bad reputation."

General Talk About AIDS and the World

A final strategy used to talk about AIDS keeps it at a distance from the relationship. Remarks were often made about the nature of the "epidemic" or the latest findings about virus transmission (e.g., "we share new information"; "talk about current events"). Some just reported general talk about magazine articles or TV programs, but it was difficult to determine what they meant by general talk. Nonetheless, the topic of AIDS was discussed but not really addressed in relation to the two partners.

Reasons for Not Talking About AIDS

It is significant that 40 percent of our sample indicated that at some time they had wanted to talk about AIDS in their relationships but had failed to do so. This failure was grounded more in concern for the impact on 1) the relationship, 2) the respondents' own discomfiting feelings, and 3) the partners' reactions. The responses taken as a whole suggest that relationships are viewed as extremely fragile and subject to instantaneous breakup upon discussion of behaviors that in any way jeopardize the perceptions each person has of the other. Furthermore, individuals who feel a strong need to be in a relationship may opt to put the needs of the relationship above their own desire for health and safety.

The reasons participants gave for not talking about AIDS appear to reinforce the findings of Baxter and Wilmot[13,14] as well as the relational talk premises of Phillips and Wood.[3] There was concern for the resilience of the relationship or its ability to rebound from sensitive discussions. Perhaps partners in this youthful sample did not have sufficient relationship skills or experience in negotiating highly sensitive issues. Thus, they were not convinced that the relationship could survive such sensitive disclosures. In this context, then, talk about AIDS would be threatening and uncertain.

According to the college students' own accounts, the primary reasons for not addressing AIDS in the context of the relationship were 1) the effects of talking on the self; 2) the effects of talking on the other and the future of the relationship; 3) the effects on an intimate mood; 4) general fear of AIDS; and 5) that the relationship was not seen as serious enough to warrant talk about such a serious issue.

Effect on the Self

While men were far more concerned with harming the possibility for a relationship, women appeared to be more attentive to their own feelings of embarrassment, fear, etc., as barriers to talk. Women reported that talking about AIDS would be "embarrassing" or awkward ("it felt weird"; "I was feeling stupid"). Men echoed many of these sentiments. One woman exemplified the explanation given by Keeling[16] for college students' failure to talk about AIDS in relationships when she noted, "I was not secure enough to ask.... Discussion of his past girlfriends was too threatening." Keeling, director of the AIDS Task Force for the American College Health Association, has reported that the most insidious deterrent to safer sexual relationships among college students is the self-esteem of the students.[16] They need the ego strength to choose to assert their health needs in the romantic arena.

Effect on the Other and the Future of the Relationship

Implicit within their statements of concern was the fear that the subjects would experience some negative feeling if they talked about AIDS. In addition, they reported being concerned with the potential impact of discussion on the other person. They did not want to "hurt the other," "insult him," "offend him," "degrade her," or "make him angry." For many, "to ask your partner is a presumption of guilt"; some echoed the feeling that "she would think I was accusing her of being a slut." Males seemed most interested in refraining from behavior that might negatively affect the future of the interaction. In a new relationship, the seriousness of AIDS as a topic of conversation might scare off potential intimates by escalating the conversation to a level with which neither party was wholly comfortable. Men in the sample were fearful that talking about AIDS would "destroy other possibilities in the relationship." Fear for lost opportunities in short-term encounters was clear in the responses, as was concern for more enduring relationships. One man wrote that he did not want to "threaten my current long-term relationship, so I didn't tell her about an interlude with a high-risk person."

> *"That some students did not talk about AIDS with a partner because they felt the relationship was not serious enough seems to be the ultimate irony."*

Effect on Intimate Mood

Also significant for these young men and women was the fear that talking directly about AIDS would destroy the mood or would happen "at the wrong time." Men seemed most cognizant of this: "It would kill the mood, destroy the heat of the moment."

General Fear of AIDS

Women also cited more general concern for the problems associated with AIDS, even if they had not talked directly about the problem. They had general questions, for example, "after an AIDS presentation at school" and "wanted more information but didn't know where to go." More specific concern about past histories surfaced as well: Subjects reported being "worried about the partner's past promiscuity."

Relationships Not Serious Enough for Talk

That some students did not talk about AIDS with a partner because they felt the relationship was not serious enough seems to be the ultimate irony. It reflects the age-old dilemma between passion and reason. Because they did not abide by the traditional rules of gradual intimacy, whereby they forego sex until they are comfortable enough with their partners to discuss the issue, they experienced a double bind.[17] While the health risk of AIDS demands protective action, they did not feel comfortable enough with each other to talk about the issue. Even though it does not seem rational in light of the dire consequences of failure to talk, men and women both described brief, sexual encounters in which this double bind was operating. Students often commented on the brevity of the relationship: "It was a one-night stand," "it was a new relationship," "I didn't want to stay attached to the person," "I didn't know her well enough," "she was a complete stranger," "too fast a relationship, we hadn't known each other long enough," "it was just a casual sexual relationship. I didn't even know her last name."

Ironically, it is in these very sorts of relationships, where individuals are unable to assess risk, that the risk may be greatest. References to strangers, "pick ups," and anonymity also suggest that because these experiences are not intended to be permanent they do not warrant serious attention. It also may be that people are choosing to ignore the implications of a failure to discuss AIDS because it is simply too stressful a topic.

Alternative Information-Gathering and Decision-Making Strategies

Talking is not the only means of gathering information about one's partner. College students in this study cited several indirect ways to test the safety of the relationship situations without confronting the potential partner. These included asking others for information about the potential risk of another; making inferences from external signs such as clothing, friendliness, or aggressiveness; setting out personal rules to follow; and generally reasoning away the risk. In this last category, there were varying degrees of accuracy in the rationales students gave for perceiving themselves to be at low risk for AIDS.

Asking Others About the Partner

First, we must examine the legitimacy of the strategy of asking others about the reputation, sexual history, and past relationships of the potential intimate. For both males and females, asking someone else what they knew about the partner was seen as the most viable option for obtaining information indirectly. Subjects argued that this network had been helpful for them before AIDS, so it must also be an effective way of discovering the potential risk of new partners. However, there is a basic difference between using this process to make a decision about dating someone and using it to determine whether the potential partner has participated in high-risk behaviors.

Because sexual practices and intravenous drug use are taboo topics for talk, we thought it highly unlikely that friends and acquaintances would have accurate information about the risk status of potential partners. Yet the students questioned others: "Asked friend if girl was nice and whether she fooled around"; "is she willing, will she go all the way?"; "ask others close to him about dating habits, lots of girls or just one?"; "ask friends in common what kind of girls he dated." While asking friends for information may produce gross indicators of sexual activity, it is harder to determine another's specific experiences. The fear of being described as a homosexual, bisexual, or intravenous drug user will prevent college males from openly discussing these behaviors with friends. Hence, the validity or safety of asking friends for information must be viewed cautiously.

Using Appearance to Judge Risk

Making judgments about the safety of another person from observations about external appearance, including dress, manner, and flirting behaviors, was preferred by males but not females. Whether they were gauging "how far she would go on the first date" or observing "how flirty or cold she is with others," "paying attention to habits they possess," or "trusting girls who dress more conservatively," males used these rules of thumb to ascertain the risk of a date.

Establishing Rules for Behavior

Some individuals had devised personal rules of conduct for their relationships that appeared, generally, to reflect concern about AIDS. Women were more likely to insist on abstinence from sexual relations until there was sufficient information to warrant intimacy. (Some were, on principle, waiting until marriage.) Males, on the other hand, believed that condoms erased the other person's past. Both men and women referred to "knowing the person well before first sexual contact." While these rules emerged from the responses of the sample of college students, we do not have information about how consistently they were actually applied across this population. Our concern is that rules are meant to be broken. They may represent good intentions but, in the heat of passion, may be forgotten.

Conclusions

Talk About AIDS

College students are talking about AIDS to some extent, but there are few indications that the quality of the talk is sufficient for a realistic negotiation of safer relationships. The level of talk reported was largely superficial: It was often about general topics, distanced from the current relationship and, in short, did not appear to involve a mature, straightforward negotiation of the serious issues related to intimacy and risk prevention. The talk that did occur was most often externally referenced, initiated in very casual or joking ways, and prompted by a media account of AIDS. This study provides very little evidence that talk about AIDS was subsequently applied to the subjects' own relationships. Communication was potentially frozen at a distant, external level.

Two possible reasons for these findings are the nature of the sample and the subjects' perceived susceptibility. The adolescents in this study were unlikely to be as cautious as their older counterparts. They perceived themselves to be invulnerable to many dangers and certainly not at risk for a disease that seems far removed from their personal spheres. Most did not know a person with AIDS. Edgar *et al.*[18] found that college students did not perceive themselves to be at risk because they feared the association with homosexuality and because the risk was not personalized. They attribute the failure to personalize risk to the fact that few college students know a person like themselves who has AIDS and to the sense of invulnerability that is common among this age group.

Furthermore, when the students did talk about AIDS with their partners they believed they were using legitimate strategies. They therefore believed that they were protecting themselves against HIV infection. In short, their perceived susceptibility is likely to be low. According to the health belief model,[19,20] behavioral change is unlikely to occur if students do not perceive themselves to be at risk.

College Students at Risk

The respondents' perception that they are not at risk for AIDS is problematic because college students are indeed an at-risk population. While only 10 percent of this sample could be considered at high risk on the basis of reported sexual activity, college students in general are at risk to the extent that sexual experimentation and recreational drug use occur on each campus.[21] The traditional social stereotypes of college as a time to "sow wild oats," "be on your own," and experiment with sexuality, alcohol and alternative lifestyles suggest some grounds for concern with regard to this population.[22] In a recent study of adolescent sexual activity, 60 percent of the respondents reported sexual activity by age 17 and 55 percent reported that they had had sexual intercourse within the past 12 months.[23] These rates of sexual activity, combined with the incidence of AIDS in young adults (21 percent of AIDS cases occur within the 20- to 29-year-old age group) offer cause for concern.

A factor that further confounds the recognition of AIDS risk is that any HIV transmission that occurs during the college years is unlikely to be identified until after graduation, given the long latency of the virus. This factor compromises the immediacy of the AIDS threat because students do not witness the symptomatic aspects of the disease; they see no evidence that they are at risk.

Refraining from Talk

Clearly, some subjects remain taboo topics for talk in college student relationships. Topics of high intensity, including AIDS, were avoided by at least 44 percent of our sample. Often, information was gathered in indirect ways, by observation or inference or even by using "secret tests," such as making "trial balloon" comments and then checking the other's response.

Some students seemed to be aware that talking about AIDS would change their relationships. In that sense, this study offers further evidence to support the constitutive perspective of relationship communication. While individuals may not be able to articulate the function of talk in relationships, it is clear that they are both aware of talk and afraid of its consequences. Some evidence of this is found in the students' reasons why they did not talk about AIDS. They said, for instance, that talking would "violate trust" or "ruin the relationship," or that this topic is "too serious." Implicitly, they were aware that once they discussed the risks of their past or present behaviors, the risk of AIDS would become a real entity that had to be faced.[6,7]

Students may be using an extra-logical reasoning process involving several levels of denial: They deny that their actions may have dire consequences, and therefore they do not have to take responsibility for their sexual behaviors. (Some do, however, report being more concerned with pregnancy than AIDS, so there is some recognition of consequences.) They deny that AIDS is a direct threat to them and bolster that denial with thoughts that "it won't happen to me," "I'll live forever," or "I don't know anyone with AIDS." The threat of AIDS can be bracketed from conscious awareness and perceived dimly as a distant threat.

Although many individuals function as if the threat of AIDS is distant, there seems to be a wholesale fear that AIDS is affecting them. Some students report changing their dating behaviors because of AIDS, being more selective about their partners, or slowing down the progress of relationships. So the educational campaigns have had some impact, although it seems that the most significant effect has been to raise levels of fear and concern rather than fostering preventive behaviors.

We can also see that some legitimate risk assessment is taking place. Some students pointed out that they had known a partner for several years, or that one or both partners had been tested, or that they refrained from certain behaviors as a rule. Those who made such statements seemed to be accurately applying knowledge about AIDS to their behavioral and relationship choices.

Finally, it disturbs us to realize that those who reported being truly concerned about AIDS and talking about it with their partners were probably at the least risk. Because of the media crucible in which awareness of AIDS has developed, an atmosphere of fear has been created, leading many who have no cause for alarm to take these threats seriously. Edgar *et al.*[24] echo this sentiment when they question the wide use of fear appeals in AIDS public service campaigns. It seems that those who have the least to worry about are talking and that those at greatest risk are not.

Implications

The willingness of people to talk about AIDS and how it affects their relationships is an important dimension for consideration by communication researchers and AIDS policy planners. Although our study has provided some insight into how college students think about AIDS and apply that thinking to their own relationships, these students are not among the groups at highest risk for AIDS. It will be important, therefore, to replicate this study of talk with members of high-risk groups, including gay and bisexual men, minority adolescents, and intravenous drug users.

While media efforts appear to have persuaded some individuals that high-risk behaviors should be avoided, they can only be described as successful if they produce real behavioral change. Along with other researchers,[18] we suggest that most individuals do not have the interpersonal skills to successfully negotiate safer sexual intimacy. Rather than expending the lion's share of AIDS education budgets on media messages that promote fear, it would seem to be more cost-effective to offer the public information about managing this extremely sensitive issue in relationships.

One of the implications of this recommendation is that sex education curricula should be revised to include training in the communication skills necessary to negotiate sexual relationships.[25] It will be important to provide models that are congruent with the cultural, sexual, and personal identities of each target population. For instance, there are clear differences in the ways men and women approach the issue of AIDS in relationships. Proportionately more of the women in our sample reported talking about AIDS in their relationships. Women seem to want more talk and are likely to take the responsibility for talking about AIDS, particularly as it pertains to the partner's relationship history. Men, on the other hand, are more likely to trust their own observations when assessing potential risks. They also seem more willing to state and act upon their biases. This gender-specific information must be incorporated into communication skills training. The same relationship skills training must also be available for those who are outside the educational system.

A crucial goal of this training will be to build the participants' self-esteem to empower them to take responsibility for their own sexual and physical health. As Keeling[16] has reported, higher self-esteem is inherently related to an individual's ability to protect himself or herself in risky sexual encounters.

While these proposals are guaranteed to incite those who oppose sex education in schools, the AIDS epidemic is now expanding in such proportions that we can ill afford the luxury of debating the moral implications of such programs. These educational programs are much easier to recommend than to implement. They are fraught with logistic complexities and it is only the maverick policy maker who would dare to operationalize them. Yet it must be done. The prospect of losing millions of human lives before this century is out mandates risk taking on the parts of school districts, public health departments, and national health figures.

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Sexuality is part of our identities. If you contracted genital herpes, how would it change your life? How would this incurable disease affect your relationships; your sexual satisfaction; your sexual identity; your self-esteem? How would you cope?

Counseling Clients with Genital Herpes

Jane Craig, a 26-year-old graduate student, was diagnosed with genital herpes a year ago. Since then, she has told only a close girlfriend and refuses to go out on dates because she does not want to disclose that she has herpes to a potential sexual partner. Jane feels ashamed and guilty about having herpes, stating "I'm just not the kind of person who gets sexually transmitted diseases." She is angry at the casual sexual contact she suspects gave her herpes without mentioning that he had the disease, and feels she has destroyed her dreams of marriage and a family. She has had four recurrences in the past year.

John Peters has had genital herpes for two years, with one mild recurrence lasting about one week. John believes his source contact for herpes was a woman he was dating exclusively for three years. Early in their dating, she had told him she had herpes but that he would not get it from her since she would not have sex when a herpes lesion was present. After his diagnosis, John confronted her but she claimed she had not had a recurrence in several months. John did not believe her and gradually they stopped seeing each other. He does not tell his many sex partners that he has herpes since, "I know when I have a recurrence and I don't have sex then; they don't have to worry about it. Why tell?"

As these cases illustrate, genital herpes creates personal havoc and can produce long-term psychosocial disability in the lives of those with the disease. Jane and John represent two cases of the estimated 20 million Americans with genital herpes (Centers for Disease Control, 1986). Each year, there are an additional 500,000 persons diagnosed with this chronic, recurrent, infectious, sexually transmitted disease (Centers for Disease Control, 1982). The media attention given to herpes in recent years has increased the fear and stigma surrounding it. In addition, new knowledge of the epidemiology of genital herpes has produced information essential for the psychiatric mental health

By W. Carole Chenitz, RN, EdD; and Janice M. Swanson, RN, PhD

The majority of those affected with genital herpes may be asymptomatic.

nurse in counseling clients with genital herpes. The goal of counseling clients with herpes is twofold: to reduce the psychosocial consequences of herpes for the affected individual, and prevention, that is, to reduce transmission of the virus from the infected to noninfected person. To accomplish this and effectively counsel these clients, nurses need information about the course of genital herpes as well as the physical and psychosocial consequences of the disease.

Genital Herpes

Genital herpes, a major public health problem, is often the first chronic disease of young adults between 18 and 40 years of age (Corey, 1983). Currently, there is no adequate control for this problem. Genital herpes is not a reportable disease to the Centers for Disease Control and, therefore, estimates of the incidence are based on a survey of private office-based physicians in the United States. This survey revealed that between 1966 and 1984 there was a 15-fold increase in private office-based physician visits for genital herpes; an increase from 29,560 to 450,570 visits with the largest proportion of those seeking care between 20 and 29 years of age (Centers for Disease Control, 1986). Prevalence rates of genital herpes are estimated at between 20% and 55% of sexually active adults (Nahmias, 1985).

Symptoms of genital herpes are painful vesicles that rupture to produce ulcers usually on the genital skin or mucous membranes. Lesions on the skin form crusts or scabs that heal within 10 to 14 days. They may be accompanied by fever, swollen glands, and other flu-like symptoms.

As a chronic disease, there are five critical, interrelated aspects of genital herpes of importance to both patients and to health professionals: its recurrent nature; the often asymptomatic transmission; the incurability; the disease as a risk factor for human immunodeficiency virus (HIV) infection; and the physical and psychosocial consequences of the disease.

Recurrent Nature of the Disease. Following a primary outbreak, approximately 88% of patients experience recurrences. Recurrences are usually less severe and of shorter duration than primary infections (Corey, 1983). The cause of recurrences is unknown but have been reported to be sunlight, fever, heat, wind, menstruation, sexual intercourse, masturbation, overexertion, illness, sleeplessness, and stress (Bierman, 1985).

Asymptomatic Transmission. Genital herpes includes both HSV-1, the virus associated with oral herpes (cold sores), and HSV-2, the virus associated with genital herpes. Recent studies have demonstrated little difference between HSV-1 and HSV-2 in producing genital herpes simplex infections (Becker, 1986). Herpes simplex virus is transmitted by contact with mucous membranes or breaks in skin with active ulcerative lesions which may or may not be visible, such as those on the cervix.

Herpes simplex virus may also be transmitted asymptomatically by persons excreting the virus with no lesions. The majority of those with genital herpes may be asymptomatic. Seroepidemiologic studies suggest that fewer than one in four persons with genital herpes are symptomatic and that transmission occurs from contact with persons who are asymptomatic or fail to recognize the disease (Mertz, 1988). In one study using type-specific serological assays for HSV-1 and 2, only one fourth of 2,000 individuals with antibodies to HSV-2 reported clinical histories related to herpes infection (Becker, 1986). In another study, only 3% of pregnant women randomly selected in an inner city hospital gave histories related to genital herpes infection, but 52% had herpes simplex virus, type 2 antibodies (Thompson, 1985). Another study reported that three fourths of source contacts of patients with primary genital herpes gave no history of genital herpes and only one third were aware they had genital herpes at the time of sexual contact. Yet, all of the source contacts had type-specific antibodies indicating prior infection (Whittington, 1985).

Incurability. No cure exists for genital herpes, although a range of treatments, including folk remedies, have been tried. Oral, topical, and parenteral forms of acyclovir have been found to relieve symptoms and to reduce the duration of viral shedding. Oral acyclovir has been found to reduce viral shedding, as well as frequency and severity of recurrences, particularly when therapy is self-initiated among frequent recurrers (Marlowe, 1985). Drug side effects from use longer than six months are unknown (Becker, 1986).

Risk Factor for HIV Infection. Infection with HSV-2 is a risk factor for HIV infection, and persons with genital herpes who have multiple partners are also at high risk for AIDS (Cannon, 1988). Herpes simplex infections in persons with AIDS also present significant clinical problems.

Physical and Psychosocial Consequences. Genital herpes infections

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are associated with cancer, abortion, encephalitis, keratitis, meningitis, urethral stricture, labial fusions, neuralgia, ascending myelitis, and lymphatic suppuration (Corey, 1983). Genital herpes infection has also been associated with premature births. Infection of the fetus with HSV during delivery may cause encephalitis, keratitis, and results in an increase in cesarean deliveries and isolation of the neonate after birth (Corey, 1983). HSV infection of the newborn ranges from 0.13 to 0.5 per 1,000 live births; symptomatic disease almost always results and 50% of infected infants die (Arvin, 1986). From 50% to 70% of newborns with HSV are born to women with no history of peripartum HSV infection (Arvin, 1986). Transmission to the neonate may occur in several ways: by contact with an infected vaginal canal; infection following rupture of membranes or use of fetal scalp electrode monitors; transplacental transmission; and contact after birth with persons who are infected with oral or breast lesions (Arvin, 1986).

When You Need Someone To Talk To

The Herpes Resource Center, founded in 1979 and affiliated with the American Social Health Association, provides services specifically for those afflicted with genital herpes. The Center's hot line offers confidential social and sexual advice by trained counselors. Representatives from the Center, state that the Centers for Disease Control estimated that there are 20 million Americans who have contracted genital herpes (HSV-2) and 50 million Americans who have oral herpes (HSV-1).

With so many Americans having this incurable disease, the Herpes Resource Center feels that there is a real need for guidance. Aside from the hot line, the Center furnishes free question and answer pamphlets for herpes sufferers and their partners, as well as directories of herpes support groups and treatment centers nationwide. The Center also has a listing of books, newsletters, tapes, and research reports which may be purchased.

For more information, contact Herpes Resource Center, Box 100, Palo Alto, CA 94302; 415-328-7710.

Psychosocial Consequences

Emotional Distress. Emotional distress as a response to genital herpes has been reported as altered perceptions of self, fear of rejection or transmission of the disease, anxiety, anger, guilt, isolation, and depression (Lukacs, 1977). Little research has been done to support clinicians' observations (VanderPlate, 1987). Surveys have found psychological distress among subjects with genital herpes associated with feelings of undesirability and fear of transmitting herpes (Luby, 1985). Subjects with genital herpes have reported loss of confidence and depression (Drob, 1985b). Houck and Abramson (1986) found women with genital herpes experienced more stress than women with other sexually transmitted diseases (STDs). Psychosocial stress has been reported in clinician anecdotes to be a major factor in triggering recurrences (VanderPlate, 1987). The few studies conducted to test this association are inconclusive. Variables associated with recurrences include a stressful experience the week preceding a recurrence; suicidal feelings; emotional stress; stressful life events and low social support; and depression, anxiety, tension, social alienation, hostility, impulsivity, and preoccupation with health concerns (VanderPlate, 1987). The results of these studies must be interpreted with caution since they are largely cross-sectional surveys of volunteers relying on subject recall. Nevertheless, these results do point out that stress and emotional factors play some role in the disease process, namely recurrences.

Sexual Attitudes, Functioning, and Behavior. A major response to genital herpes involves sexual attitudes, functioning, and behavior. Surveys have shown that individuals with genital herpes report reduced intimacy and sexual pleasure, inhibited sexual freedom, increased impotence, and other sexual problems (Luby, 1985). They also feel less sexually desirable (Drob, 1985b). Overall tension regarding sex and marked reduction in number of sexual contacts and celibacy have also been reported (Luby, 1985).

Interpersonal Relationships. Genital herpes has been reported as a negative influence on enjoyment in meeting persons of the opposite sex and in establishing a normal relationship (Luby, 1985). Individuals also report a lack of support from other persons in learning to manage herpes and ethical dilemmas about whether to have sex, when, with whom, and if a partner should be informed. Casual sex with an uninformed partner while in a symptom-free state and excuses for not having sex during symptomatic periods have both been reported, as well as postponing or giving up having children (Drob, 1985b). Finding a new sexual partner was more difficult among women with recurrent genital herpes than among women with other STDs, a finding the authors attribute to the severe, chronic, incurable nature of this disease compared with other STDs (Houck, 1986).

Coping and Adaptation. Coping with genital herpes requires adjustment to living with the disease and the prevention of transmission. Manne and Sandler (1984) investigated how individuals cope with and adjust to genital herpes. In a study of 152 subjects with genital herpes recruited from newspaper advertisements in a southwestern metropolitan area and self-help groups around the country, Manne and Sandler (1984) found that predictors of poor psychological adjustment were cognitive coping mechanisms, wishful thinking, characteristic self-blame, attribution of blame on the person who gave the subject herpes, and repeated use of disease management strategies. Obsessive use of these strategies, which often fail, creates more stress and a state of "learned helplessness"

Genital herpes, the "new scarlet letter," brings to public attention extremely personal and private activity.

according to the authors. Social support was associated with better psychological adjustment.

Assessing and Counseling the Client With Genital Herpes

The first element to be assessed is the person's knowledge of herpes and its transmission and consequences. As the current study of young adults' adaptation to genital herpes has found, a second critical component that must be assessed in the client with genital herpes is the individual's attitude toward self, personal relationships, and sexual functioning. Attitude toward self includes self-image, self-esteem, and sense of personal integrity. Genital herpes can negatively affect the individual's self-image and self-esteem. The media, while playing an important role in increasing public awareness of genital herpes, has also facilitated the identification of herpes as the "new scarlet letter." Genital herpes brings to public attention, as does AIDS, extremely personal and private activity. The individual with genital herpes no longer has the privilege of privacy, but must now disclose a sexual history that contains a disease transmitted by a sexual partner. In addition, having genital herpes places the individual at risk for being stereotyped and rejected once the disclosure of herpes is made.

Stigmatized with the "new scarlet letter," a diagnosis of genital herpes causes psychological distress and social fear. The stigma of herpes and the judgment made about the morals of those with the disease are images and values held by those who have the disease. As one young woman who was recently diagnosed with genital herpes stated, "I am not the type of girl who gets things like herpes." How then does she feel about herself now that she has herpes? In a well known study, Luby and Gillespie (1981) describe a sequence of reactions to the diagnosis. First, there is shock and emotional numbing followed by a search for a cure. Then, awareness of the chronic nature of the disease leads to feelings of isolation, anger at the person who transmitted the disease, and fear about the impact of herpes on sexuality. A sense of contamination leads to the "leper effect" and depression. In some, underlying psychopathology is exacerbated. Feelings associated with the diagnosis of herpes are anger, disbelief, fear, vulnerability, isolation, helplessness, frustration, and depression (Bierman, 1985).

Genital herpes is a chronic disease and, as with all chronic diseases, requires adaptation that includes the formation of a new identity (Connor-Greene, 1986; Manne, 1984). Unfortunately, herpes carries with it negative connotations and, hence, the new identity may be one that is negative. For example, in a sample of women with herpes, Stubbs (1981) found that the majority stated that herpes had negatively affected their feelings of self-worth. In addition, self-blame was related to greater maladjustment to herpes (Manne, 1984). A positive reconception of self, that is, a positive new identity, needs to be formed. This may be difficult for a person who has strong moral or religious beliefs about STDs and for a young adult who is still forming a sexual identity (Connor-Greene, 1986).

For an individual to have a healthy self-image, the self must be separated from the disease and the new identity cannot be seen as "sick" or "dirty," which are images often associated with STDs, particularly genital herpes. The new identity includes genital herpes, but is not ruled by it. Many people may need assistance in forming this new identity. A national survey of persons with herpes revealed that respondents suffered depression, isolation, lowered self-esteem, decreased work performance, and decreased sexual desire. One fourth of this sample reported destructive thoughts and 18% stated that herpes was a major cause for the end of a relationship (American Social Health Association, 1981). Clearly, some people may experience great difficulty adapting to herpes and forming a positive new identity that enables them to live, love, and work successfully.

In a study of coping with herpes, Manne and Sandler (1984) found that

> "higher levels of support were correlated with less symptomatology and better self-esteem. The perceived helpfulness of support was correlated with better overall adjustment and fewer sexual problems. In addition, those who perceived the attitude of family, friends, and medical workers as more negative reported a greater degree of depression, more sexual problems, poorer self-esteem, and poorer overall adjustment."

In addition, feelings of anger and rage at the person who transmitted the disease must be dealt with. Anger is a corrosive emotion if left to smolder into resentment. Manne and Sandler (1984) found that of those studied with herpes, blaming those who gave the subjects herpes was correlated with overall symptomatology. Displacement of the anger onto another partner or turned inward unto the self are common reactions when anger is not accepted. This will affect self-esteem and relationships with others.

Over time, one third of the 74 men and women with herpes surveyed by Luby and Klinge (1985) became well adjusted to the condition. However, two thirds reported significant sexual dysunction, diminished self-esteem, social isolation, and a sense of loss of control caused by recurrences. From the available data, counseling those newly diagnosed with herpes is recommended. The attitude of the health professional making the diagnosis is important, since any hint of a negative, judgmental attitude will be amplified by the emotionally sensitive, newly diagnosed person. Although the diagnostic interview may not be the appropriate time for referral to counseling, the individual's feelings about self and partner need to be explored and counseling should be made available.

Sexual Behavior

The type of sexual behavior in which an individual with herpes will engage is critical and must be assessed during counseling. A range of behavior is possible from abstinence to use of barrier contraception when having intercourse. The efficacy of modifying one's sexual behavior, however, is theoretical; hepatitis B vaccine is the only well-studied ethod of prevention for STDs (Stone, 986). Methodologically, studies have failed to verify reported sexual behavior of subjects and to measure contacts to exposed persons. As studies have shown, people are willing to or have changed their behavior out of fear of contracting or transmitting HSV-2 (Aral, 1985). Sexual decisions may be reached by the individual alone or with the support of others.

Safer Sex. Abstinence prevents the transmission of genital herpes, but is not recommended as a method of prevention for sexually active persons (Stone, 1986). Monogamy also carries no risk of contracting HSV-2 if neither partner is infected and both are monogamous. Identifying persons infected with HSV-2 may be impossible, therefore reducing the number of sexual partners and avoiding those who have multiple partners is recommended. Avoiding certain practices such as anorectal intercourse will prevent abrasions or tears in the delicate rectal epithelium. Avoidance of oral-genital sexual practices ill prevent cross-infection with HSV-1 HSV-2. Asking a partner direct uestions about possible infection is recommended.

FIGURE
Techniques to Assist Clients to Communicate About Genital Herpes

Permission Giving

To bring up and talk about herpes. Exploring the experience: How has it been for them on other occasions when they have had to talk about herpes? If they have no experience, what are their fears about telling others? What will happen? How will the partner respond?

Information Giving

Discuss ways of telling. Give positive affirmations to confirm a positive self-image.

Coaching

Supporting and encouraging clients to talk.

Role Playing/Practicing Disclosure

What to say? How to say it? When to say it? How to role play with friends? The use of a support system, such as friends or support group. Disclosure statements can be practiced or rehearsed with others. One such statement is, "I like being with you and enjoy spending time with you. Most people have heard of genital herpes and have some ideas about it. It's important to me that you know that I have genital herpes and that I would like to talk about it."

Preventing transmission of genital herpes is necessary for coping and living with the disease. Recommendations for prevention and transmission are the use of condoms and spermicides containing nonoxynol-9 (Feldblum, 1988) and disclosure to sexual partners of the disease condition (Drob, 1986; Drob, 1985a).

Use of Barriers. Barrier methods of contraception may protect the partner from contact with a penile or cervical lesion, urethral discharge, and mucosal secretions, or may chemically inactivate the virus. Condoms are recommended for use. Laboratory studies that have simulated friction during intercourse have found condoms to effectively prevent the transmission of HSV.

The herpes simplex virus is about 200 nm in diameter and does not pass through latex or natural skin condoms (Feldblum, 1988). Condoms must be used carefully. When a genital lesion is present, sexual activity should not occur. Lesions may be unrecognized, however, or asymptomatic shedding may occur. The condom should be used each time before intercourse and should be placed before the penis has any contact with the vulva. Natural vaginal lubrication or a water-soluble lubricant such as K-Y jelly is necessary if the condom is not lubricated to prevent friction and possible breakage. Following intercourse, the condom should be removed carefully and the genital area and hands washed with soap and water before sexual contact is continued. It is important to realize that the condom will protect the female partner only from lesions or shedding from the penis; lesions on the testicles, thighs, or anal or pubic areas will not be covered. In turn, only the male partner's penis will be protected from his partner's cervical lesions or shedding.

Spermicides containing the active ingredient nonoxynol-9 such as jellies, foams, suppositories, and the sponge have been found in laboratory studies to inactivate HSV-2 (Feldblum, 1988). Spermicides may be used in conjunction with condoms for greater protection should the condom break. The use of condoms and spermicides are prac-

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Fear of rejection by a potential partner is a major impediment for disclosure of genital herpes.

tical, safe, and their use should be recommended for prevention of the transmission of genital herpes.

Communication

Although sexual freedom has characterized the 60's and 70's, sexual behavior may not have affected willingness to talk about sex and sexual activity. As Masters and Johnson point out, "we have spent 25 years trying to disabuse people of their inhibitions about discussing their sexuality, and apart from the fact that people are slightly more comfortable with the subject . . . it is as if we have made no mark at all" (cited in Leishman, 1987).

Chapman and Sughrue (1987) believe that although sex is still a sensitive and personal area, it is no longer a taboo subject since clients are bringing their sexual concerns to clinicians. This, however, is no evidence that clients are willing to discuss sexual concerns with potential or actual partners nor that willingness to disclose a sexual history that includes an STD, such as herpes, has increased.

The goal for the clinician is to assist the individual with the verbal skills necessary to disclose the existence of herpes to a potential partner. Individuals with herpes suffer not only psychological distress, but fear: fear of rejection when the disclosure of herpes is made and fear of contagion, that is, transmitting herpes to others.

Fear of rejection by a potential partner is a major impediment for disclosure of genital herpes. This fear may eclipse the fear of contagion and, hence, the individual may remain silent and not disclose his or her condition, or may choose not to engage in any sexual activity at all. Both of these options lead to difficulty since in the former, the individual finds himself in an intimate relationship that lacks a basic ingredient for intimacy, that is, trust. In the latter, the individual casts himself off from a central feature of humanity—sexual intimacy. In either case, these options do not promote the individual's choices, but instead narrow potential.

This choice was placing D.J. in great distress. She had been dating a man she met in school and felt it was fine not to tell him she had herpes since she was not serious about him. However, she became emotionally involved with him and she then felt the need to tell him she had herpes. Her distress was based on her fear that he would judge, devalue, stereotype, and finally reject her. Indeed, anyone making this disclosure may be rejected. The Figure lists techniques to assist clients to communicate about genital herpes. However, once this fear is explored and the reality of rejection faced, the individual can better make the disclosure. Another client, S.T., avoided her fears by not dating men she considered, "nice, the way I used to be." Her self-image was negatively affected by herpes.

Summary

The epidemic of genital herpes requires nurses to diagnose and treat human responses to this health problem (American Nurses' Association, 1980). It also creates many opportunities for nurses, particularly in the realm of counseling and education.

Given the changing epidemiology of genital herpes and the psychosocial consequences, nurses need to keep abreast of new information so that they may assist people to live with the disease and teach the prevention of transmission of the disease. Recent information about mild and asymptomatic cases of herpes infections has serious implications for counseling and education of persons with genital herpes. The emergence of this "silent" dimension of herpes infections means more difficulty in diagnosis and treatment. All persons with genital herpes should be assessed for their physical and psychological responses to the disease and information should be given to combat misconceptions, to alleviate fear, and aid in preventing transmission.

The most significant implication of mild or asymptomatic herpes is the greater risk of transmission. The public needs to be informed about the practice of "safer sex" as a routine measure to prevent herpes, as well as AIDS and other STDs. Given the widespread and epidemic proportions of herpes, persons should be counseled to use condoms whenever they engage in sexual activity with a partner. In addition, co rect use of condoms must be taugh. Nurses have an important role to play in counseling clients with genital herpes and in preventing the disease.

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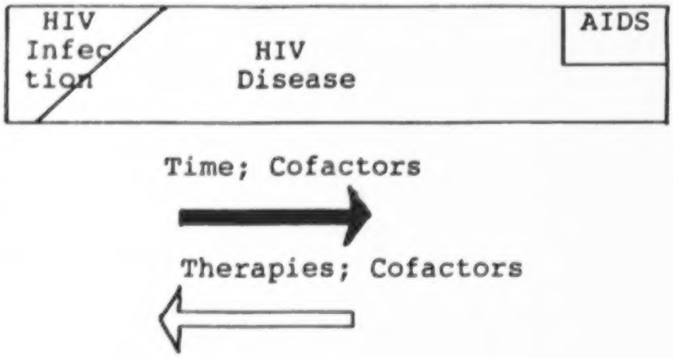
Spectrum of HIV Infection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HIV Disease
AIDS
Time; Cofactors
Therapies; Cofactors

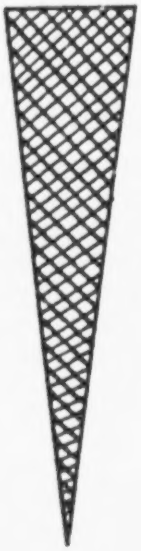
PHASES OF HIV INFECTION

Acute HIV Disease	Asymptomatic HIV Disease ("HIV Positive")	Chronic Symptomatic HIV Disease (AIDS Related Complex)	Advanced HIV Disease (AIDS)
days-weeks	years	months-years	months-years

ROUTES OF TRANSMISSION OF HIV

1. Sexual Contact
    a. Unprotected anal or vaginal intercourse; ?? oral intercourse
    b. Artificial insemination
2. Blood
    a. Needle sharing for any reason
    b. Contaminated blood or blood products
    c. Accidents in health care
3. Perinatal
    a. Intrauterine
    b. Peripartum
    c. Breast feeding

RELATIVE RISK OF SEXUAL ACTIVITIES - assuming no protection



HIGH

Receptive anal intercourse
Insertive anal intercourse
Receptive vaginal intercourse
Insertive vaginal intercourse

LOW

Oral sex on male with ejaculation
Oral sex on male without ejaculation
Oral sex on female

NONE

Intimate kissing
Casual kissing
Touching, massage, rubbing
Masturbation

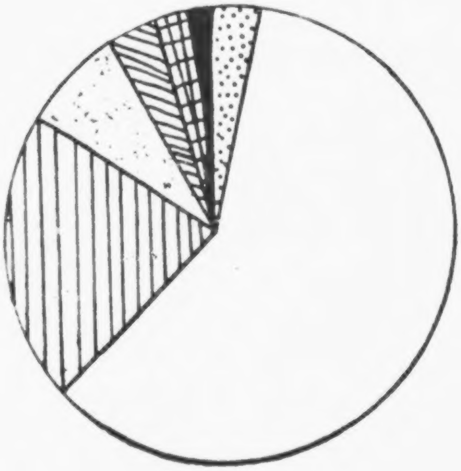
PROJECTED TOTAL CASES OF AIDS

Cumulatively since 1981

End of Year	Cases
1989	123,000
1991	250,000
1993	500,000

AIDS CASES, BY TRANSMISSION CATEGORIES

Adults and adolescents
United States
Cumulatively since 1981
Data current through September 1989



○ Homosexual/Bisexual male-----61%
▥ Intravenous drug user--------22%
▒ Homosexual male/IV drug user--7%
▧ Heterosexual contact----------5%
▦ Transfusion-associated--------2%
● Hemophiliacs-----------------
░ Undetermined*-----------------3%

*undetermined category includes:

- died before investigated
- lost to follow-up
- refused interview
- still under investigation
- males claiming prostitute cont
- 1 health care worker

EVOLVING TRANSMISSION CATEGORIES

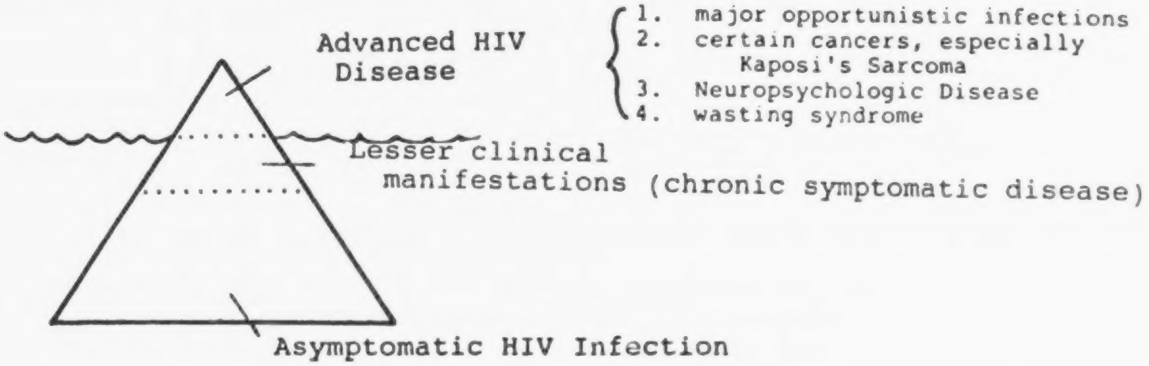
AIDS, Adults and adolescents
United States

	New cases only Year Ending September 1988	New cases only Year Ending September 1989
Homosexual/Bisexual Male	58%	57%
Intravenous Drug User	22%	23%
Homosexual Male/IVDU	7%	6%
Heterosexual Contact	5%	5%
Transfusion-associated	3%	2%
Hemophiliac	1%	1%

CASES OF FULL-BLOWN AIDS ON CAMPUS

- Few traditional age undergraduates
- More graduate, professional, and returning students
- Mostly faculty and staff

THE "ICEBERG" OF HIV DISEASE


Advanced HIV Disease
1. major opportunistic infections
2. certain cancers, especially Kaposi's Sarcoma
3. Neuropsychologic Disease
4. wasting syndrome
Lesser clinical manifestations (chronic symptomatic disease)
Asymptomatic HIV Infection

ACHA/CDC NATIONWIDE HIV SEROPREVALENCE SURVEY-1988/89

Number of campuses: 19
Number of blood samples: 16,861
Number (percent) positive: 30 (0.2%)
Range on 19 campuses: 0 to 0.9%
Number of males: 28/30 (93.3%)
Number of females: 2/30 (6.7%)

THE ICEBERG OF AIDS OF A CAMPUS

Assuming 0.2% Seroprevalence

Number of Students	Number with AIDS	Number with Chronic Symptomatic Disease	Total Number Seropositive
1,000	0 - 1	0 - 1	2 - 3
5,000	0 - 1	0 - 2	8 - 12
10,000	1	1 - 3	18 - 24
20,000	1 - 2	2 - 5	36 - 44
50,000	2 - 4	5 - 10	90 - 110

TESTS FOR HIV INFECTION

Antibody: Screening - ELISA (Enzyme-linked immunosorbent assay)

Confirmatory - Western Blot, or immunofluorescent antibody (IFA)

Antigen: P24 antigen

Gene: polymerase chain reaction (PCR)

Virus: reverse transcriptase assay

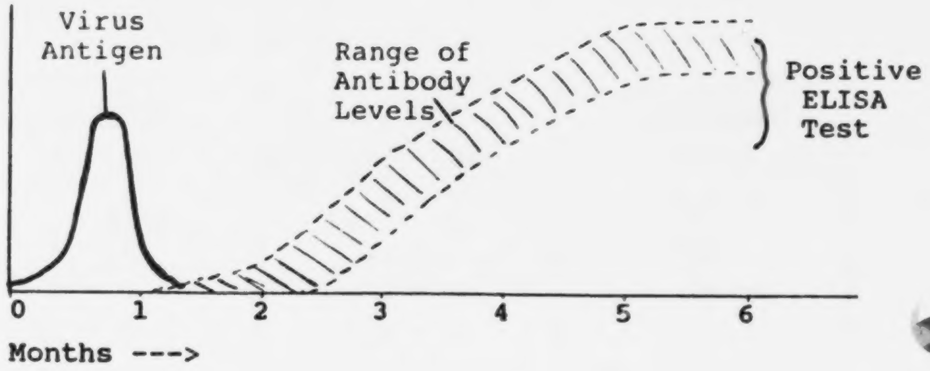
REASONS FOR EARLY TESTING

1. Protection of other people
2. Early medical and immunologic monitoring
3. Anti-viral therapy
4. Vaccine-preventable disease
5. Prophylaxis or surveillance for opportunistic infections
6. Modification of co-factors
7. Travel limitations

SAFETY IN HIV ANTIBODY TESTING

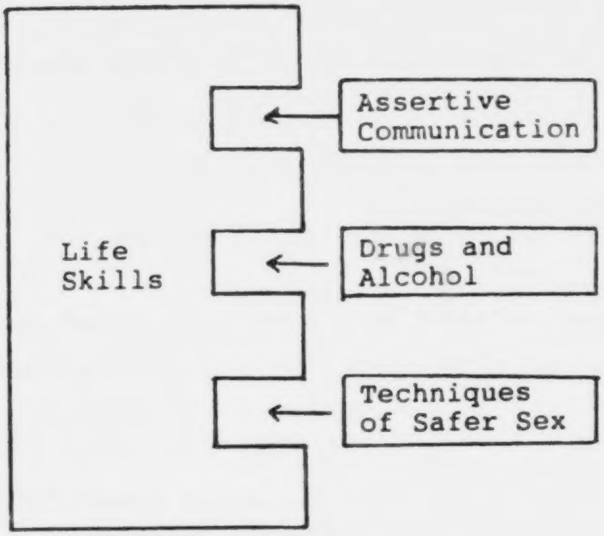
1. Social safety - protection of confidential information
2. Psychological safety - pre-test and post-test counseling and support

TIMING OF ANTIBODY RESPONSE TO HIV



LIFE SKILLS FOR PREVENTING HIV INFECTION

1. Self-esteem
2. Decision Making
3. Intimacy; developing relationships
4. Stress management
5. Coping with uncertainty
6. Managing alcohol and drugs
7. Awareness of social standards, cultural norms, gender socialization differences.


Life Skills
Assertive Communication
Drugs and Alcohol
Techniques of Safer Sex

KEY SUB-SKILLS IN PREVENTING HIV INFECTION

1. Assertive communication (skill building required)
2. Separation of alcohol or drug use from sexual activity
3. Techniques of safer sex
    a. Intimacy without intercourse
    b. Intercourse only with condoms
    c. Nonoxynl-9

IMPORTANT AXIOMS OF AIDS EDUCATION

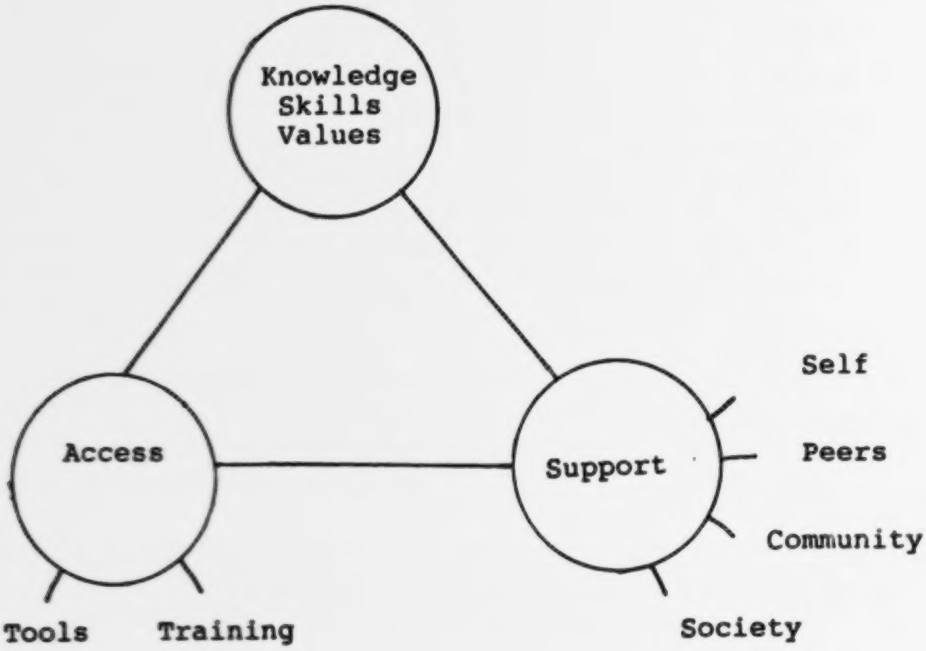
- INFORMATION is not EDUCATION
- EDUCATION is not BEHAVIOR CHANGE
- AIDS education must include:
    - skill building
    - skills practice
    - positive feedback for behavior change
    - maintenance strategies
    - adaptation of skills to individual lives
- AIDS education programs are becoming:
    - more diverse
    - more dependent on small groups
    - more peer-based
    - more resource-demanding
    - less reliant on a single "big program"
- Successful AIDS education programs will be:
    - specifically targeted to segmented audiences
    - repetitive and ongoing; available and accessible; innovative and creative
    - explicit and direct, using clear language
    - culturally relevant and sensitive
    - delivered in the media and vocabulary of the audience by appropriate credible messengers
    - focused on self-esteem for all students
    - aware of important social issues in AIDS:
        discrimination
        harassment
        homophobia
        racism
        sexism
    - part of campus life everyday
- **Three key questions:**
    - **1. Are your students involved?**
    - **2. Is the program integrated into campus life?**
    - **3. Is it controversial?**

SELF ESTEEM

Components:
1. Sense of uniqueness
2. Inherent value as an individual
3. Worthiness for life, health, future, potential
4. Acceptance of self

Important roles in AIDS education:

1. Connects awareness to a personal acceptance of both risk and the ability to protect oneself
2. Connects acceptance to accountability to promote health and life.


Knowledge
Skills
Values
Access
Support
Self
Peers
Community
Society
Tools
Training

Copyright 1989, American College Health Association

Michael David, a Boston artist, has created a series of twenty-four drawings titled Bearing Witness. He has graciously allowed Dr. Keeling to use some of them in his presentation and is interested in exhibiting the entire collection on college campuses. For further information contact him at (617) 424-1250.

BRIEF RISK INTERVENTION (BRI)

A shorter and more condensed version of AIDS prevention developed by TASC (Treatment Alternatives to Street Crimes).

BRI can be used when there is limited time to educate a client about risk of exposure to the HIV and the facts of AIDS. It may be the only method that intake staff, detox staff, hospital emergency room staff, mental health staff and probation staff are able to use consistently, not having long periods of time to work intensively with a client.

Like CPR, BRI can save lives. You need not be a doctor or nurse to educate someone about the risks of AIDS.

The underlying assumption is that the target person is not infected with HIV, but at risk for it.

1. BRI is individualized because information which is relevant to the client is presented. Information gleaned from the intake form may provide the counselor the base for the individualized instruction (if client has never used or shared needles, this area of transmission information may be short or eliminated) while client may have indicated a number of different sex partners which will inform the counselor that sex and HIV infection need to be discussed more widely. The intervenor always presents options that are relevant to the individual client, rather than blanket recommendations.

2. BRI is non-invasive - No personal questions are necessary;
client can reveal as much or as little as he/she wants. Intervenor uses material at hand, gaining a sense of probable risk area, BRI thus does not rely as much on trust/rapport relationship as in-depth risk assessments and counseling do.

3. BRI is motivational - as it is face-to-face, one human being caring about another. BRI seeks to reinforce the positive and give clients a sense of options and control over their lives. The intervenor constantly praises the client for:

- Interest in/or knowledge about AIDS
- Current behaviors which avoid HIV exposure (monogamy, not shooting up, participation in drug treatment, etc.)
- Willingness to consider options and make changes
- Anything else that reduces risk or has potential to motivate further positive behaviors

Brief Risk Intervention Counseling Hints

Depersonalize interview by using "we" or "some people" instead of "you", thereby increasing client's level of comfort. Example: instead of saying, "You may want to start using condoms" try to say "Many people are now using condoms when having sex." This indirective, impersonal style may feel awkward to the counselor who has been trained otherwise, but this detachment provides necessary protection of privacy for the client - privacy which will make it possible for him/her to hear what you are saying.

Concentrate on the purpose of BRI which is self-protection rather than altruism, since we are assuming the client is uninfected we want to find ways to keep him/her that way. Presuming the client is infected would raise defenses, denial and emotions which would impede the process of risk counseling.

Use open questions (questions that you cannot answer by saying yes or no) to elicit client involvement and helpful information. Open questions let client depersonalize the material. For example: What if somebody had shared needles with someone else who he knows has AIDS? Refer to people in general.

Use language comfortable to you. Once you are comfortable with the language necessary in AIDS risk education, BRI will become second nature to you just as other intake processes are.

Exclude words like "homosexual," "promiscuity," "sero-conversion," etc. After each bit of information you give the clients, ask whether there are any questions. Listen closely to answers and questions because they will give you a hint of areas acceptable and unacceptable to client. Avoid focusing on the unacceptable.

In order to change a client must:

Believe there is a good reason
Believe there is a benefit
Believe the change is doable

BRI Process

The assumptions you make from other intake data may leave room for error, you need to check with client what is important to her/him. Whenever client indicates an interest, respond promptly.

Assure client of confidentiality. Put away pen, paper. Explain that this risk assessment is done with all clients.

Using information you have gathered from other intakes, consider whether the risk may be related to:

- IV drug use with needle sharing
- Physical/medical condition (already has had hepatitis, lost weight, etc.)
- Substance abuse treatment history

- Male-to-male sexual contact
- Criminal justice system prostitution record
- Time spent in jail, prison or armed forces
- Runaway adolescent
- Marital status
- Sex with any of the above
- Medical history of sexually transmitted diseases
- Residence in NY, NJ, Central Africa or Caribbean
- Male partner who has been in jail

For persons used to working with clients on a longer term process, the BRI may at first appear frustrating. But, you are not dealing with the entire spectrum of risk awareness. You may be the first and introductory person to the longer process of AIDS awareness. It may also be that BRI will be the only personal AIDS prevention message this individual will receive. The alternative is that they will get nothing.

BRI is planting a seed. The client may react as if he or she does not care, or may be angry and hostile. Thus, you will never know the full impact of your message, but you will know from other human interaction that if you get the message across that you care it may be the beginning of the process of change.

Bella H. Selan

PATIENT EDUCATION FOR HIV INFECTION PREVENTION: THE PROJECT ARIES APPROACH

In 1986, the National Institute of Mental Health funded a research project entitled, "Behavioral Training to Reduce AIDS Risk Activities" at the University of Mississippi Medical Center in Jackson, MS. The project's purpose was to study the impact of an intervention program designed to assist gay or bisexual men change those aspects of their behavior that created high risk for HIV infection and subsequent AIDS.

The intervention program was called Project ARIES. ARIES being an acronym for AIDS Risk Intervention Series. The program was based on the assumption that while education is a cornerstone for AIDS prevention efforts, knowledge about AIDS and risk behaviors alone is not always sufficient to produce meaningful change in activities which pose HIV infection risk. Behavior patterns which are longstanding, highly reinforced, socially coerced, and which carry negative illness consequences temporarily distant from the immediately-reinforced activity which creates risk may be particularly difficult to change.

Just as skills training-behavioral assistance can help persons modify such health-threat patterns as overeating, cigarette smoking, cardiovascular risk, and exercise adherence, achieving meaningful reduction or cessation HIV/AIDS high-risk practices requires development of certain behavioral competencies. These skills can be taught to groups of gay men through provision of specific information and rationale for AIDS risk reduction; sexual assertiveness training to refuse high-risk sexual activities or coercive propositions; self-management training relevant to risk reduction; and development of positive lifestyle goals, health-consciousness, and belief in the efficacy of risk behavior change.

The following material will address the program's portion on self-management training. During three of the program's 12 sessions, group participants are taught skills needed to identify and then modify personal high-risk behavior patterns. This is done by analyzing past situations in which participants had engaged in high-risk behavior and identified such factors as setting, mood state, intoxicant use, partner characteristics, and other antecedents preceding past risky encounters.

In the sessions, group leaders and other participants present self-management strategies that could be used to alter risk antecedents. These strategies included practical suggestions (e.g., keeping condoms readily available if sexual activity might occur, curtailing alcohol use in conjunction with sex, socializing with friends rather than seeking sexual partners when lonely, avoiding settings associated with casual sex), and cognitive modification strategies (self-reinforcement for taking steps to reduce risky activities, generalizing and rehearsing self-statements which reinforced the efficacy of risk-reduction change, and problem-solving ways to handle antecedent "triggers" associated with part high-risk sexual activity). Participants were encouraged to practice these strategies between sessions.

The elements of the self-management program are: (1) analysis of antecedents (triggers) to personal past risky behavior; (2) problem-solving alternatives to personal risk triggers; (3) implementation of risk-reducing alternatives; (4) cognitive modification to develop self-guidance and self-reinforcement patterns to sustain changes; and (5) making practical environmental modifications to facilitate risk reduction change. See the next page for examples of triggers and alternatives.

A copy of the manual developed in conjunction with this project may be obtained by contacting:

Jeffrey A. Kelly, Ph.D.
Department of Psychiatry and
Human Behavior
School of Medicine
University of Mississippi Medical Center
2500 North State Street
Jackson, MS 39216-4505

Manual Title: Behavioral Group Intervention to Teach
AIDS Risk Reduction Skills

EXAMPLES OF TRIGGERS AND ALTERNATIVES TO HANDLE TRIGGERS

SCENARIO 1: Going to a bar and drinking too much preceding high-risk sex.

Triggers Identified:	Alternative to Triggers:
--going to bar	--go to places other than bars
--going to bar alone	--go to bar with a friend
--drinking too much	--drink less
--seeking sex	--if drinking too much, defer sex
--feels lonely	--widening circle of friends, developing other ways to meet people --do not equate sex as a way to counter loneliness

SCENARIO 2: High-risk behavior develops in a steady relationship

Triggers Identified:	Alternative to Triggers:
--failure to discuss precautions in advance with partner	--discuss importance of safety with the partner to identify and resolve conflict
--lessened vigilance because of relationship status	--reminding oneself that AIDS is caused by a virus and that viruses don't "care" about relationship status of people
--running out of condoms	--have condoms available before sex
--incorrect comparison to others	--reminding oneself that precautions are desirable and needed even if some other couples don't choose to make changes
--believe that precautions unnecessary given relationship status	--if so, both individuals must get tested, learn their serostatus, and stay monogamous

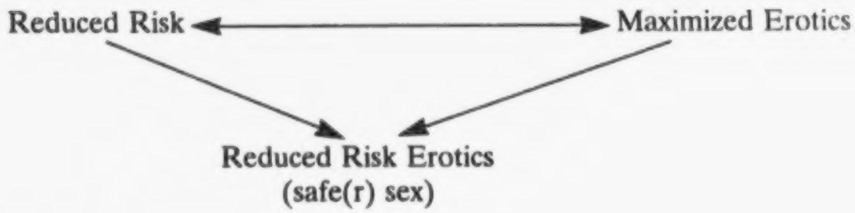
THREE KEY ELEMENTS OF AIDS PREVENTION PROGRAM

Patient Education → Changes → Knowledge

Personal Risk Assessment → Changes → Attitudes

Individual Risk Reduction → Changes → Behavior
Health Promotion

STD/AIDS PREVENTION
SEXUAL RISK REDUCTION



Reduced Risk

Maximized Erotics

Reduced Risk Erotics
(safe(r) sex)

PROCESS

OF

SEXUAL RISK REDUCTION

(Reduced Risk Erotics)

Risk Assessment

Knowledge Acquisition

Body Awareness

Peer Reinforcement

Mental Rehearsal

Access

Self-esteem

Communication Skills

Practice

Eroticism

Routine

PUBLIC EDUCATION & PREVENTION

Walter F. Batchelor
AIDS Community Training Conference

Seven Major Points to Consider

WHO should you target? Be specific and somewhat limited in deciding on your target audience for each component of a public education and prevention program. This allows you to use the most appropriate language, pictures, and medium of communication.

BECAUSE of what specific risks and problems relating to HIV/AIDS? Remember that not all groups are equally at risk due to sexual behavior, drug use, medical procedures,fear, family involvement, and so forth. Don't ignore sexual behavior when communicating with gay men.

WHERE and through what kinds of media should you base your campaign? Depending on the target audience, you should consider brochures, posters, television, radio, newspapers,neighborhood flyers, guest speakers at professional meetings,etc. Big posters may catch a person's eye, but they don't transmit much information. Many individuals are afraid to pick up an informative brochure in front of other people --due to the stigma attached to AIDS. Consider the overall context of your message and audience when choosing your medium.

WHAT should the message include? Facts alone are rarely enough to make people understand the real meaning of AIDS. Generalizations leave people unsatisfied in most cases.Consider the full range of topics that ought to be included to communicate your entire message and to make the message important to the reader.

HOW do you want your target audience to respond? Give practical,reasonable advice about how each individual can reduce risk.Simple slogans such as "Just Say No" are not easily accepted.Unrealistic suggestions such as "know partner's sexual history" fail to take into account human nature. Workable and culturally-relevant suggestions are a must.

WHY should your target audience be interested in AIDS? What is their motivation to be concerned? Is it because of personal risk, professional risk, the risk to women and children, the changing nature of sexuality, or some other reason? Tie your message into the possible/probable motivations of your target audience.

SO WHAT? What is the intended outcome of your education and prevention campaign? Can you define it in measurable terms?Will you be able to do evaluation to find out changes in attitudes, sexual behavior, sharing of needles, infection-control precautions, clinical services, etc? Will you be able to count the number of brochures sent out... and the number that are actually read? It is not easy to evaluate AIDS programs, but it is far from impossible as long as you consider issues of confidentiality, privacy, embarrassment,and the difficulty of precise measurement. Planning your evaluation before you begin your program will give you the best information about the outcome of your program. Use evaluation to make your program better by scheduling feedback early and at regular intervals, if possible. Using evaluation only at the end of a program is never as useful as ongoing feedback.

SEXUAL HISTORY GUIDELINES

1. Family Sexual History

- How was the relationship of your parents?

- What were the messages in your family for males and females about:
  - Touch
  - Body
  - Feelings
  - Anger
  - Control
  - Communication
  - Sex

- How was affection displayed in your family?
  - Between parents
  - To you
  - Verbally/physically

- Sexual discussion:
  - Comfort discussing sex or asking question family
  - Ever discussed with friends
  - Subject of jokes and embarrassment
  - Considered dirty

2. Sexual Experiences

- As a Child:
  - Remember when had first sexual feelings
  - Masturbation/self pleasuring
  - Touching others/others touching
  - Watching/showing
  - Genital experiences
  - Same sex/opposite/both
  - Sexual trauma: rape, incest

- As an Adolescent:
  - Feel attractive, popular
  - Have sexual feelings
  - Masturbation/self pleasuring
  - Touching others/others touching
  - Watching/showing
  - Genital experiences, first intercourse
  - Same sex/opposite/both
  - Important sexual/emotional relationships

Sexual trauma: rape, incest

- As an Adult:
    - Important sexual/emotional relationships
    - Masturbation/self pleasuring
    - Touching others/others touching
    - Watching/showing
    - Sexual fantasies
    - Erotic/pornographic literature/movies
    - Genital experiences
    - Same sex/opposite/both likes/dislikes (even forced to do)
    - Types of activities
    - Amounts/frequency Sexual communication
    - Sexual trauma
    - Sexually-transmitted diseases
    - Contraception, condom use
    - Sexual dysfunction: non-orgasmic, premature ejaculation, impotence, vaginismus, dyspareunia, etc.
    - Importance of sex in your life

3. Concerns of Self, Partner(s)

- Sexual
- Relationships
- Health
- Goals

4. Image

- Body
- Relationship

SEXUAL HISTORY GUIDE - SHORT FORM

1. Establish rapport. Ask client how he/she feels talking about sex. Use non-judgmental terminology.

2. Number of Partner(s)/High-Risk Partner(s)

3. Types of Activities:

- * Partners same/opposite/both sexes
- * Giver/receiver (receiver at highest risk)
  - anal intercourse
  - vaginal intercourse
  - oral sex
  - rimming (mouth on anus)
  - fisting (hand/arm in anus or vagina)
  - urine/feces play (in/or body)
  - toys (inside body; own toys or share)
  - blood-drawing activities (whipping, biting, scratching, piercing, menses, etc.)

4. Use of drugs with sex

5. Types of activities done to get drugs

RISK ASSESSMENT FORM

Leland G. Wessell, M.D., M.P.H.

The following Risk Assessment Form is both a clinical and an educational tool, designed to assist clients and health care providers in understanding the behavioral factors that influence an individual's risk of HIV infection. Clinicians can use the score that results from a client's careful and honest answers in teaching risk reduction and in following and reinforcing its success. The higher the score, the greater the risk; decreasing scores over time denote risk reduction. While a given score does not reflect the absolute risk of being infected, it gives both the clinician and client an impression of the likelihood of infection if a given set of behaviors persists.

This Risk Assessment Form may help clinician and client reach a decision as to whether to perform the test for antibody to HIV. It increases awareness about behaviors that may lead to exposure to the virus; since it is **not** retained in the medical record, but rather goes home with the client, it may be used as a reference by the client after the visit with the clinician has ended. The periodic use of this form to assess risk by the individual client may provide a tangible motivational tool for risk reduction.

As is true of any tool, this form can be misused. Because of the very sensitive nature of the information it requests, it must NEVER be included in medical records. The form is intended to be used as a tool for promoting effective client education in a one-on-one, client/clinician setting and not as an end in itself. *Each individual participating in this risk assessment should be told in advance that (1) he or she will keep the form and (2) that no information transmitted verbally to the care provider will be included in the record.* **The importance of this Risk Assessment Form is in education, not record-keeping.**

Risk Assessment Form

This form is confidential – it is not a permanent part of your medical record.

Many factors must be considered in assessing your health and fitness. Among these are: (1) your risk of acquiring or transmitting any sexually transmitted disease (STD) and (2) your use of psychoactive chemicals in connection with sexual activity, a practice that can increase your risk of acquiring an STD. STDs considered here include, but are not limited to: gonorrhea; syphilis; genital herpes; genital warts; chlamydia; hepatitis B; giardiasis; and infection with HIV, the virus that causes AIDS.

The first two questions are biographical in nature and are not part of the risk assessment score. They are intended to guide your provider in making the best possible appraisal of your health. The remaining 11 are the scored behavioral risk assessment. Please be honest in responding to the questions — we assure you that this document will be handled with the utmost confidentiality by you and your health care provider only. Please feel free to discuss the results with your provider. You may retain the survey for your own reference. *In any event, it will not be placed in your medical record.*

There are 13 questions listed below. Please check the one single answer that best describes your preferences or activities.

A) How long have you been sexually active? ___________

B) Your most recent consistent sexual partner experience
male ____ female ____ both male and female ____

1. How many sexual partners *per month* in the last year?
3 _____ 5 or more
2 _____ 2-4
1 _____ 0-1

2. How many partners *per month* in the year previous?
3 _____ 5 or more
2 _____ 2-4
1 _____ 0-1

3. The kinds of sexual contacts I have are:
3 _____ one-time or anonymous "tricks," "one night stands," groups, or prostitutes
2 _____ multiple times with two or more partners
1 _____ exclusively with one partner

4. I have sexual encounters or contacts most frequently
3 _____ in baths, bookstores, parties, "massage parlors," "spas," public restrooms, autos
1 _____ in my or my partner's home

5. The frequency with which I use drugs or alcohol to enhance my sexual encounters:
3 _____ frequently
2 _____ occasionally
1 _____ rarely/never
Please circle drug used: "poppers" (amyl or butyl nitrates), alcohol, marijuana, hallucinogens (LSD, mushrooms), "angel dust" (PCP), amphetamines, barbiturates, quaaludes, ecstasy, eve, cocaine, crack or _____________ (please fill in others)

6. I have injected myself with one or more of the above drugs in the past five years.
4 _____ yes
1 _____ no

7. I have sexual encounters most frequently in:
3 _____ New York, Los Angeles, San Francisco, Miami, Washington, Dallas, Houston, Newark, Atlanta
2 _____ other large urban areas (Boston, Philadelphia, St. Louis, Seattle, San Diego, etc.)
1 _____ small cities, towns, rural areas

8. Those kinds of sexual activities I practice most frequently are (please circle specific activities):
4 _____ vaginal or anal intercourse without a condom, oral-anal contact (rimming), direct fecal or urine contact (scat or water sports), or manual-anal contact (fisting)
3 _____ "protected" vaginal or anal intercourse (use of condoms and spermicides)
2 _____ oral-genital contact (fellatio or cunnilingus)
1 _____ masturbation, massage, body rubbing, kissing

9. My current sexual partner and I have discussed our previous sexual behavior and experiences with each other.
4 _____ No
1 _____ Yes

10. I negotiate with sexual partners for safer sexual practices.
   4 _____ No
   2_____ Sometimes
   1 _____ Yes

11. I ask potential sexual partners about their use of drugs and steroids, especially their use of needles.
   4 _____ No
   2 _____ Sometimes
   1 _____ Yes

Add up the numbers from each question (1-11) and see the key below to determine your level of risk.

My score is _______.

If you answered "1" (the last option) for question 8, deduct 3 points.

Total adjusted score _______.

KEY:
17 or more: You appear to be at high risk for developing STDs, including HIV infection, and for possibly developing dependence on psychoactive substances. You should visit your health care provider immediately to discuss your risk of these dangers.

12-16 points: You appear to be at moderate risk for developing either an STD or chemical dependence and are encouraged to lower your overall risk by altering the behaviors that resulted in high scores on some of the questions. See your health care provider for any questions or concerns you may have regarding your risk.

11: You are at low risk for problems and are encouraged to continue your healthy behavior. Please feel free to contact your health care provider at any time for updated information regarding safer sex, AIDS, or any other issues.

This scoring system was designed to: (1) increase your awareness of STDs and the risk factors associated with acquiring or transmitting STDs, (2) stimulate self-evaluation of your health and your sexual lifestyle, and (3) encourage your taking responsibility for your health and the health of your sexual contacts. **This questionnaire is yours to keep and review. It will not go into your medical record even if you bring it to your health care provider.**

KEY ISSUES TO BE REVIEWED WITH ALL CLIENTS INDIVIDUALLY OR, IF NECESSARY, IN GROUP REGARDING AIDS AND PREVENTION.

* Why AIDS should be of concern to everyone

* How HIV is and is not transmitted and what the client really believes about this

* Why prevention--avoidance of HIV infection--is so important and what behaviors are high risk exposures

* The difference between HIV infection and a diagnosis of ARC and AIDS (spend a lot of time on this)

* The meaning of "asymptomatic carrier"

* The meaning and implications of a "long latency period" or incubation period

* What a person can do to keep healthy, even if infected

* What a person should not do if infected

* The major symptoms of AIDS and ARC

* The client's feelings, thoughts, misperceptions and beliefs about AIDS and sex, AIDS and drugs and major anxieties about infection risks or symptoms

* The client's responsibilities about transmission

* Whether the client has already made any lifestyle changes or behavioral changes as a result of the AIDS situation

Bella H. Selan

REDUCING RISK THROUGH SAFE SEX PRACTICES

Reducing risk for AIDS may mean making changes in sexual practices, but it does not mean denying the sexual part of one's life. We believe that intimacy, both sexual and emotional, is necessary as we move toward a more healthy regard for our own bodies and those we love.

Sexual practices are classified in three categories: SAFE, POSSIBLY SAFE, and UNSAFE.

- SAFE -

Most of these activities involve only skin-to-skin contact, where transfer of virus is unlikely from one person to another unless there are breaks in the skin.

* Mutual masturbation (male and female)
* Social kissing (dry)
* Body massage, hugging
* Body-to-body rubbing (frottage)
* Light S & M activities (without bruising or bleeding)
* Using one's own sex toys (do not share sex toys): Keep your toys clean and don't share them with others. If they weren't designed to go in you, don't put them there.

- POSSIBLY SAFE -

In these activities small amounts of certain body fluids may be exchanged causing some risk. This risk is increased in proportion to the number of contacts.

* **Anal intercourse with condom (fucking with condom).**There should be minimal chance for transfer of virus from one person to another if the condom does not break and spillage of semen into the rectum is prevented. The risk is further reduced if one withdraws before climax. Also use water-based lubricants (like K.Y. Jelly) which come in sealed tubes, packets or pump tops that can't spread fecal germs. Do not use spit, and avoid oil-based lubricants such as Crisco or Vaseline, which may destroy the condom. Never reuse condoms (rubbers).

* **Fellatio interruptus (sucking - stop before climax).**Being sucked is probably no danger for you unless there are any cuts on your penis to be infected by mouth germs. But to protect your partner - don't cum in their mouth.

Since it is unknown whether pre-ejaculate fluid contains an AIDS agent, there is some risk in this practice. Using a condom during sucking reduces the risk.

* **Mouth-to-mouth kissing (French kissing, wet kissing).**Saliva is not known to contain large amounts of the AIDS virus. Therefore, it seems unlikely that AIDS is transmitted in saliva. If either partner has open mouth or lip sores, risk may be increased.

* **Urine contact (water sports).**If urine contacts only the unbroken skin, risk may be low. Urine should not be taken by mouth or rectum.

* **Vaginal intercourse with condom.**The same precautions should be observed as with anal intercourse with condom.

* **Oral-vaginal contact (cunnilingus).**The extent of risk from this activity is not clear. If menstruation is occurring, risk is probably enhanced.

- UNSAFE -

These activities involve tissue trauma and/or exchange of body fluids which may transmit an AIDS agent or other microbes. They carry high risk unless the sex partners have been monogamous and healthy for five years or more.

* **Receptive anal intercourse without condom (being fucked).**AIDS seems to be transmitted through semen as well as blood, and perhaps feces. During anal intercourse, injury occurs to rectal tissue, allowing direct access of semen or pre-ejaculate fluid to the bloodstream. Studies have indicated that this practice has high correlation with acquisition of Kaposi's Sarcoma and immunological defects.

* **Insertive anal intercourse without condom (fucking).**The risk of acquisition of AIDS agent through this practice is unknown, but some studies indicate that it is less risky to the insertive partner (top man) than the receptive partner (bottom man) since no semen is received by the top man. However, the risk of exposure to blood and feces is high, and it is well known that other sexually-transmitted diseases can be acquired in this manner.

* **Manual-anal intercourse (fisting).**An early study indicated a direct correlation between fisting and AIDS for both active and passive partners. The rectal tissue can be damaged during this activity, which would allow direct access for semen to the bloodstream if fisting were preceded or followed by anal intercourse. The insertive partner's hand is exposed to blood or blood-contaminated feces and infectious agents may enter through breaks in the skin. The risk may be reduced by use of a glove and the absence of semen.

* **Fellatio (sucking).**If semen is ingested, risk is increased as the AIDS agent may be present in the semen. There is a possibility of absorption of

the agent through membranes of the mouth, especially if sores are present. Risk is reduced by withdrawal before climax.

* **Oral-anal contact (rimming).**AIDS may be transmitted by blood-contaminated feces. This act will certainly transmit parasites, hepatitis, and various forms of dysentery. There may be risk to the receptive partner. If open fissures or sores are present, risk is increased.

* **Vaginal intercourse without condom.**There are case reports of transmission of AIDS to women whose sex partners had AIDS or were in high-risk groups. If properly used, condoms should greatly reduce the risk.

General Factors

Now is the time to start taking care of your health and your partner's. Eat well, learn about nutrition. Get enough sleep every night. Get plenty of exercise and learn how to handle stress. Get regular check-ups.

Drugs and Alcohol

You need to be concerned about drugs and alcohol even though they aren't considered a direct cause of AIDS. Research shows that alcohol, speed, marijuana and poppers damage the immune system, leaving you open to disease that you might otherwise be able to fight off, and possibly make you more susceptible to AIDS. Also, drugs and alcohol can impair your judgment and damage your ability to make wise decisions. When you get high, you are likely to be tempted into sexual activities which are riskier for AIDS. So, cut down or eliminate your alcohol or drug use.

Now is the time to use those imaginations we value so much. Remember, it's what you do that's important, not just the number of partners. The choice is yours. Some people are responding by not having sex. Others are realizing that by using your creativity and imagination you can have great sex that is both healthy and sensual.

Some information from this handout was taken from brochure written by the Scientific Affairs Committee of the Bay Area Physicians for Human Rights.

For reprints of the brochure, contact:

The San Francisco AIDS Foundation
333 Valencia Street, 4th Floor
San Francisco, CA 94103

DRUG ABUSE INFORMATION

Drug abusers currently constitute the risk group with the second highest number of victims of AIDS and HIV infection. This group is potentially the hardest group to reach with education and risk reduction messages. There are many reasons for this, the foremost being the illegal subculture of drug use itself.

HIV counseling in drug treatment centers offers some unique opportunities to educate this population of people at risk for HIV infection and AIDS. The best way to educate drug abusers is in a treatment program where counseling can begin. Counselors in drug treatment centers usually have a long-term relationship with their clients, as opposed to the one-time counseling sessions common in STD clinics. In this situation they can follow-up on the clients and involve family members in various ways.

Many drug abuse treatment facilities are debating whether to offer HIV antibody testing on site. The biggest advantage of offering testing on site is the convenience and reliability of patient compliance. A client is much more likely to agree to testing if it is done immediately than if they have to travel to another site to have the test done. There is also less chance of confidentiality being compromised if the client only has to deal with one facility. However, if testing is done on site, there should be enough resources to provide high quality pre-test and post-test counseling and support services to clients who need further help. All staff members should be provided basic information about AIDS, HIV infection, and infection control procedures.

USING CONDOMS

1. Condoms do not provide 100% protection against pregnancy and sexually-transmitted diseases such as AIDS. However, properly used, condoms can reduce the risks of becoming pregnant or infected.

2. Consistently using FDA-approved latex condoms offers the best protection against disease. Condoms made of animal membranes(sometimes called "natural") may be more likely to allow germs to pass through.

3. Condoms with a lubricant containing nonoxynol-9 have an additional chemical barrier against disease. Use only water soluble lubricants. Do not use oil-based lubricants or saliva. Oil-based lubricants, such as cooking oil or petroleum jelly, can damage the condom.

4. Never use outdated condoms. Always check the expiration date on the package.

5. Always store condoms in a cool, dry place. Heat can damage a condom.

6. Never use a condom more than once.

7. The correct way to use a condom is to remove it from the package and roll it down onto the erect penis, leaving a space at the tip to catch the semen. Don't unroll the condom before putting it on.

8. Use a condom from start to finish. Don't wait until you're ready for intercourse to put the condom on. Withdraw the penis while it is still erect. If the penis goes soft while still inside a partner, the protection can be lost.

9. When removing a condom, make sure you don't spill any of these men. Also make sure you don't allow any semen to come in contact with any cuts or sores.

10. Dispose of used condoms by flushing down a toilet or putting in a trash bag.

INVENTORY OF BEHAVIORS FOR HIV RISK REDUCTION

These behaviors are stated in terms of the actions to be taken in preventing the spread of the HIV and in promoting general good health.

LIST ONE: Behaviors appropriate for primary and secondary prevention.

1. Do not engage in sexual activities in which semen, vaginal secretions, or blood are exchanged.
   a. Anal or vaginal intercourse
   b. Oral ingestion of semen
   c. Oral contact with penis or vulva (fellatio or cunnilingus)

2. If exchange of semen, vaginal secretions, or blood is not avoided:
   a. Limit the number of different partners with whom such exchanges occur. b. Limit the number of such exchanges with a single partner, if the HIV antibody negative status it not clearly known.

3. If engaging in anal or vaginal intercourse, use a condom and a spermicidal, water-based lubricant.

4. Do not engage in oral-anal contact (rimming).
   a. If engaging in this behavior, use a barrier, i.e., a dental dam, to cover the anus.

5. Do not engage in anomanual contact (fisting).
   a. If engaging in this behavior, use a latex glove that will cover all of the hand and/or arm to be inserted.

6. If engaging in oral contact with the penis or vulva is not avoided:
   a. Cover the penis with a condom.
   b. Cover the vulva with a barrier such as a dental dam.

7. Do not share intravenous needles with others.
   a. Clean needles and other paraphernalia with bleach/water solution between users and uses.

8. Eliminate or reduce the use of so-called "recreational" chemicals.

9. Know the sexual and drug use history, patterns, or habits of all potential sexual partners.

10. Maintain or begin a regular physical fitness program.

11. Maintain or begin a regular, balanced diet.

12. Maintain or begin adequate sleep/rest patterns.

13. Reduce or eliminate stress and, if unable to accomplish individually, seek professional assistance.

14. Discuss sexual preferences and limits with potential partners.

15. Seek and maintain a personal social support system.

LIST TWO: Behaviors appropriate for secondary prevention.

1. Obtain regular medical check-ups as recommended by health care provider.

2. Find a knowledgeable health care provider with whom there is rapport.

3. Do not embark upon treatment programs without consultation from provider.

4. Do not fragment health care.

SOURCE: (This material is adapted from) R.K. Bolan, "Health Education Planning for AIDS Risk Reduction in the Gay/Bisexual Male Community: Use of the PRECEDE Framework," presented at the International Conference on AIDS, Atlanta, GA, 1985.

HEALTH PLAN

REDUCING THE RISK OF HIV INFECTION AND ENHANCING GENERAL HEALTH

STEP 1 ASSESS YOUR HEALTH BEHAVIORS.

Get a clear picture of your current health practices and determine which changes will have a positive effect on preventing HIV infection and promoting your good health.

Look at . . . sexual activity drug and alcohol use stress social support nutrition and exercise attitudes and self-concept

Put it all together. Be specific about what you need to change. Change means: do more of some behaviors or less of other behaviors.

STEP 2. DEVELOP A HEALTH PLAN.

Set a behavior goal (what you want to change) and develop a strategy (i.e., how you're going to change the behavior).

Select a goal which is meaningful to you.Ask yourself, "What change in my health behavior will most effect my chances of preventing HIV infection?" or"What do I do now which most endangers my health?"

Hints for Selecting a Strategy:

- What has worked for you in the past?- What is your change style, i.e., "cold turkey" or "slow-but-sure"?- What approach best suits the type of behavior you want to change. (e.g., how to meet a new sexual partner or how to start cleaning needles)- Be honest. If you fool anyone, it's only yourself.- Get feedback. Talk with your friends about what you're planning to do and encourage them to tell you what they think.- Take responsibility. In the final analysis, the decision is yours.

STEP 3. IMPLEMENT THE HEALTH PLAN. Carry out the plan and use a behavior contract.

A contract is simply an agreement that a person makes with him/herself (and perhaps another person) to make certain changes.

A contract will include an agreement (i.e. the behavior to be changed), a time span for making the change, and consequences (i.e., what will happen if you do reach your goal and what will happen if you don't). In thinking about consequences, identify things you enjoy and be sure they're things you have control over.Ask your friend to help you carry out your plan.

Re-evaluate the plan from time to time. Make changes when you need to.

REMEMBER. . . you've made a commitment which is important to you! Stick with your commitment. You can change your behavior!

SOURCE: Peter B. Goldblum, "An Integrated Approach to Health: Power in the Face of AIDS," unpublished manuscript.

KEY QUESTIONS

To Ask About the Use of Alcohol and Other Drugs

Who to ask?. . . . Everybody!

How often do you use alcohol, cocaine, marijuana, heroin, etc.?

How often do you use a drug by injection (into a vein, muscle, or just under the skin)?

If any injection: How often do you share the drug injection equipment?

(The needle, syringe, cotton, cooker, and water -- all can have blood contamination.)

How often do you use alcohol or other drugs when sexually involved? Or vice versa?

(The greatest jump in risk seems to be with any use of alcohol or other drugs with sexual behaviors. Safer sexual behaviors take a lot of negotiations, planning, and coordination -activities difficult when using alcohol or other drugs.)

How often have you forgotten what you did while using alcohol or other drugs?

("Blackouts" are memory failure for periods of time usually associated with heavy alcohol use. It needs to be assumed that high-risk behaviors are engaged in during blackouts!)

How often do you use sex to get drugs or to make up for drug-related difficulties?

TWO QUESTIONS HIGHLY CORRELATED WITH DIAGNOSABLE ABUSE:

1. Have you ever felt you had a problem with your use of alcohol or other drugs?

2. Have you used alcohol or other drugs in the last 24 hours?

SOURCE: Dan Bigg, CCSAC HIV Consultation and Training Service
(708) 724-3832

How to Assess the Risk of HIV Exposure

MARY E. JEWELL, M.D., Wyoming AIDS Educational Training Center
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The physician must screen patients for risk of exposure to the human immunodeficiency virus (HIV). This requires direct and specific questioning about blood product exposure, sexual practices and use of intravenous drugs. If risk factors are uncovered, patients must then be counseled on how to minimize their risk. The screening process is potentially uncomfortable for both the physician and the patient. However, intensive educational efforts, including behavioral changes, are necessary to reduce the number of HIV-infected individuals.

Approximately 1 to 1.5 million people in the United States are presumed to be carriers of the human immunodeficiency virus (HIV), and most of them do not know it. By 1991, an estimated 80 percent of new cases of acquired immunodeficiency syndrome (AIDS) will be distributed in areas outside those that now have the highest incidence.[1] Therefore, all physicians must learn how to take an appropriate history to elicit risk of HIV exposure.

Physicians and their patients must discuss sensitive and personal issues that deal with sexuality, death, disability and behavior that may not be within the accepted norms of society. The difficulty of this task should not be underestimated for either party.

Only 10 percent of physicians surveyed in California asked their new patients enough questions to identify those at high risk for exposure to HIV.[1] It can be presumed that physicians in less endemic areas also are not taking an adequate history to elicit risk of HIV exposure. Asking patients if they had received a blood transfusion before 1985 or if they are hemophiliac presents no difficulties. Inquiring about sexual behavior and drug use requires more expertise.

Importance of Sexual History

Even with the emphasis placed on the HIV epidemic, physicians still are not taking adequate sexual histories. Only half of the physicians surveyed in California obtained sexual histories.[1] A survey of physicians in an Iowa family practice residency showed that only one-third took sexual histories.[2] Many physicians were not trained in medical school or residency to take a sexual history. However, they must now learn how to make discussions about sexuality part of their routine history-taking practice.

There are several reasons why physicians may not elicit a sexual history. They are often tempted to leave a sensitive area alone because of time constraints.[2] Some physicians have personal prejudices, fears or discomfort in discussing sexuality with elderly, disabled or homosexual patients or with individuals engaging in extramarital or premarital sex.[3] Physicians must identify their own weaknesses and at least present a neutral attitude to the patient while asking questions. It is important for physicians to watch their body language, voice inflections and reactions, as these may reveal value judgments more than the words themselves.

Patients are often receptive to answering questions about their sexual history. The Iowa study[2] found that 91 percent of patients thought it was appropriate for the physcian to obtain a sexual history. Some patients, however, may not want to shock the physician by being truthful in this area.[4] They may not give straightforward answers if they sense disapproval from the physician. Studies have shown that 27 to 51 percent of male homosexual patients have not revealed their sexual orientation to their physicians.[5]

If a physician is not aware of an underlying sexual problem, related problems may be misdiagnosed. Insomnia, headaches, backaches, urinary problems, depression or vague somatic complaints can often mask a sexual problem. More sexual problems are diagnosed when a sexual history is provided.[6] In addition, a sexual history will elicit the risk of exposure to a sexually transmitted disease and is the single most important means of determining whether a patient is at risk for HIV infection.[1]

Early signs and symptoms of HIV infection can easily be missed if the diagnosis is not considered. For example, a young man with a cough may have *Pneumocystis carinii* pneumonia, rather than the more typical viral syndrome or Mycoplasma pneumonia; however, the correct diagnosis may elude the physician who does not know about the patient's sexual practices. Routinely obtaining a sexual history will help the physician consider a broader spectrum of disease processes.

OBTAINING A SEXUAL HISTORY

The question "How is your sex life?" is not a good way to start a discussion about sexual practices. It is often helpful to begin with a qualifying statement to let the patient know why it is important to inquire about such a sensitive issue. The patient must be allowed the choice of not answering a particular question or of having a question rephrased. One example of a qualifying statement is: "An area of health often neglected by physicians in the past is sexual health. It is increasingly apparent that to fulfill our responsibility to patients, this must receive attention. Therefore, I am going to ask you a number of questions about sexuality."[3] Another example is: "I am going to ask some personal questions that I ask all of my patients. I believe they are important so that I can take care of you appropriately."[2] Alternatively, the physician might say: "Recently, we have become aware of certain medical conditions, such as AIDS, that may be related in part to a person's sexual practices. Therefore, I am going to ask questions about your sexual practices."[5]

In some cases, a less direct question may be appropriate initially: "Is there anything about your lifestyle—such as travel, sexual practices, diet or drug use—that might help me to diagnose your medical problem?"[5] After this introduction, a more direct line of questioning is less likely to be misinterpreted.

After initiating a discussion of sexual behavior, it is important for the physician to speak in terms the patient understands and to be nonjudgmental. The patient should be given the opportunity to express his or her feelings and should be helped to cope with the potential stress of discussing sensitive issues. In some cases, referral for additional counseling may be appropriate.

Labels such as "gay," "straight" or "bisexual" may reveal the personal prejudices of the physician. In some situations, however, these terms may convey a certain degree of understanding on the part of the physician and may facilitate further discussion. Different racial and ethnic groups have different definitions for these terms. Black and Hispanic men, for example, may not consider themselves gay if they practice anogenital-insertive intercourse, but may consider themselves gay if they practice anogenital-receptive intercourse.[7] A person who is bisexual, or who has had only infrequent homosexual encounters, may answer "no" when asked, "Are you homosexual?"[1]

The physician should never assume anything; assumptions lead to errors. Marriage does not guarantee that a person is monogamous or heterosexual. Being handicapped or elderly does not exclude a person from sexual activity.

DIRECT QUESTIONS

Patients are commonly asked, "Are you, or have you been, sexually active?" This question is sometimes misinterpreted by patients. Teenagers may infer that the physician is condoning sexual activity and may be embarrassed if they are not sexually active. A more neutral question for adolescents may be, "Have you maintained your virginity?"[8]

"Do you have sex with men, women, both or neither?" is more a direct question and avoids the assumption that someone is exclusively heterosexual or homosexual. The next questions should be, "Do you have more than one sexual partner?" and "What do you know about the sexual activities of your partner or partners?" The physician must ask the patient whether the sexual partners are bisexual, intravenous drug users, hemophiliacs, blood transfusion recipients, and whether they have, or have had, multiple sexual partners. It is important to know the total number of sexual contacts, as well as whether these contacts represented single or multiple encounters and whether they were with a known person or an anonymous person. It must be ascertained whether the patient's sexual contacts are an open or a closed group. The more contacts there have been with an HIV-infected individual, the greater the risk of transmission of the virus (*Table 1*). Depending on the sexual partner, multiple sexual encounters with just one person could reduce the risk of HIV infection.

The geographic location of the sexual encounters is important, because some areas in the United States have a much higher incidence of HIV infection than others. In addition, the risk of HIV infection increases when a sexual encounter occurs in such settings as gay bars, bathhouses and health clubs, singles bars, adult movie theaters and adult bookstores.[7]

Male and female prostitutes both have a higher risk of HIV infection. Asking the patient, "Have you ever exchanged money or drugs for sex?" may be less threatening to the patient than using the term "prostitution."[1] In addition, this term may have different meanings for different cultural groups.

The patient must be asked about a past history of sexually transmitted diseases. Ulcerative venereal diseases, such as herpes and *Haemophilus ducreyi* infection (chancroid), are associated with a higher rate of HIV transmission.[9] It is important to know which anatomic parts were infected with the venereal disease. For example, rectal gonorrhea in a man would be a greater HIV risk factor than urethral gonorrhea.

If any high-risk sexual activity is disclosed, the date of the activity should be established. HIV is generally thought to have entered the United States in 1978.[5] However, a documented case of HIV infection occurred in St. Louis in 1968,[10] and cases have been documented in Africa as early as 1959.[11]

SEXUAL PRACTICES

In talking with patients, the physician will find it helpful to divide sexual practices into three different categories: affectional practices, usual sexual practices and extraordinary sexual practices.[7] Affectional sexual practices are those that carry a low risk of transmission of HIV, such as hugging, dry kissing, body contact with no mucous membrane contact and mutual masturbation.[10] Female homosexual activities often fall within this category. The incidence of sexually transmitted diseases is lower in homosexual women than in either

TABLE 1

Risk of HIV[*] Infection for Heterosexual Intercourse in the United States

	Assumptions			*Estimated risk of infection*	
Risk category of partner	*Prevalence of HIV infection*	*Infectivity*[†]	*Condom/spermicide failure rate*	*1 Sexual encounter*[‡]	*500 Sexual encounters*[§]
HIV serostatus unknown					
Not in any high-risk group					
Using condoms	0.0001	0.002	0.1	1 in 50,000,000	1 in 110,000
Not using condoms	0.0001	0.002	—	1 in 5,000,000	1 in 16,000
High-risk groups[‖]					
Using condoms	0.05 to 0.5	0.002	0.1	1 in 100,000 to 1 in 10,000	1 in 210 to 1 in 21
Not using condoms	0.05 to 0.5	0.002	—	1 in 10,000 to 1 in 1,000	1 in 32 to 1 in 3
HIV seronegative					
No history of high-risk behavior[¶]					
Using condoms	0.000001	0.002	0.1	1 in 5,000,000,000	1 in 11,000,000
Not using condoms	0.000001	0.002	—	1 in 500,000,000	1 in 1,600,000
Continuing high-risk behavior[¶]					
Using condoms	0.01	0.002	0.1	1 in 500,000	1 in 1,100
Not using condoms	0.01	0.002	—	1 in 50,000	1 in 160
HIV seropositive					
Using condoms	1.0	0.002	0.1	1 in 5,000	1 in 11
Not using condoms	1.0	0.002	—	1 in 500	2 in 3

[*] —*HIV indicates human immunodeficiency virus.*

[†] —*The value 0.002 represents an upper limit on the probability that an infected male will transmit HIV to an uninfected female during one episode of penile-vaginal intercourse with ejaculation. Female-to-male infectivity may be lower, and infectivity for anal intercourse when genital ulcers are present may be higher. The value is a group mean and may vary among individuals.*

[‡] —*The risk of infection for one encounter is the product of the values in columns 2 through 4 of this table ("Assumptions").*

[§] —*The risk of infection for 500 encounters is* $\text{column 2} \times [1-(1-\text{column 3} \times \text{column 4})^{500}]$.

[‖] —*High-risk groups with prevalences of HIV infection at the higher end of the range given include homosexual or bisexual men and intravenous drug users from major metropolitan areas, and hemophiliacs. Groups with prevalences at the lower end of the range include homosexual or bisexual men and intravenous drug users from other parts of the country, female prostitutes, heterosexuals from countries where heterosexual spread of HIV is common (including Haiti and central Africa), and recipients of multiple blood transfusions between 1983 and 1985 from areas with a high prevalence of HIV infection.*

[¶] —*High-risk behavior consists of sexual intercourse or needle sharing with a member of one of the high-risk groups.*

Reprinted from Hearst N, Holley SB. Preventing the heterosexual spread of AIDS: are we giving our patients the best advice? JAMA 1988;259:2429. Copyright 1988, American Medical Association.

homosexual men or heterosexual men or women.[5]

Direct questions must be asked about the patient's usual sexual practices. These include vaginal-penile intercourse, oral sex (is the person the passive or active partner?) and anal sex (is the patient the passive or active partner?). Physicians must also obtain information about any extraordinary sexual activities that the patient may only rarely practice. Questions must refer to specific body parts and specific actions, using simple language. "Does your partner ever put his finger into your rectum?" is one example of the type of question that must be used.

Table 2 lists sexually transmitted diseases and medical conditions associated with specific sexual practices.

PREVENTIVE PRACTICES

It is not enough merely to ask patients whether they use condoms. The physician must also discuss the proper use of condoms, because many individuals have contracted diseases as a result of improper

TABLE 2

Specific Sexual Practices and Associated Diseases

Sexual practice	*Diseases*
Close body contact, hugging	Pediculosis pubis, scabies, fungal infections
Masturbation	Physical abrasions
Douches, lubricants, spermicidal products	Allergic reactions, rectal fatty tumors
Amyl and butyl nitrate inhalation ("poppers")	Amyl and butyl nitrate burns, contact dermatitis
Active fellatio	Physical abrasions, oral gonorrhea, herpes, nongonococcal pharyngitis (including Chlamydia), oral warts (condyloma), syphilis, hepatitis B, HIV infection, enteric diseases, lymphogranuloma venereum, granuloma inguinale, chancroid
Passive fellatio	Physical abrasions, bites, scrapes, herpes, nongonococcal urethritis (including Chlamydia), gonorrhea, *Neisseria meningitidis* infections, HIV infection
Active anal intercourse	Nongonococcal urethritis, *Escherichia coli* infections, gonorrhea, hepatitis (A, B, non-A, non-B), herpes, warts (molluscum and condyloma), syphilis, HIV infection, trichomoniasis, epididymitis, prostatitis, fungal infections, lymphogranuloma venereum, granuloma inguinale, chancroid, cytomegalovirus
Passive anal intercourse	Physical proctitis, rectal gonorrhea, rectal warts, nonspecific proctitis (including Chlamydia and others), herpes, syphilis, hepatitis B, HIV infection, trichomoniasis, Corynebacterium infections, lymphogranuloma venereum, granuloma inguinale, chancroid, cytomegalovirus, candidiasis
Active anilinction ("scat")	Enteric diseases (shigellosis, *E. coli* infections, hepatitis [A, B, non-A, non-B], amebiasis, giardiasis, salmonellosis, helminthic infections), oral warts, oral gonorrhea, syphilis, HIV infection, lymphogranuloma venereum, granuloma inguinale, chancroid
Passive anilinction ("rimming")	Rectal herpes, syphilis, HIV infection
Passive anodigital contact (fist/finger insertion)	Internal scrapes, anal sphincter tears, perforations of the colon, acute abdomen, HIV infection
Active anodigital contact (fist/finger insertion)	Shigellosis, *E. coli* infections, salmonellosis, enteric diseases, HIV infection
Sex toys and devices (e.g., penis rings, dildos, leather, clamps)	Allergic reactions to metal, plastic, rubber or leather, friction dermatitis, physical torsions, varicoceles, fungal infections, lost rectal objects, testicular strangulation
Sadomasochism, piercing, bondage	Lacerations, cutaneous infections, trauma
Group sex	Same as for anilinction

Adapted from Gremminger RA. Taking a sexual history. Wis Med J 1983;82(11):20-4.

condom use. *Table 3* presents information to be reviewed with patients. It must be stressed that latex, not natural skin, condoms must be used for protection. Nonoxynol-9 has excellent HIV viricidal activity and should be used along with the condom.

In many spheres, the use of condoms has been promoted as "safe sex." Condoms are by no means absolutely safe—and this point must be stressed with patients. In one study,[9] ten heterosexual couples were followed; one partner in each couple was HIV-infected. Although all ten couples consistently used condoms for vaginal intercourse, three reported HIV seroconversions in the previously negative partners.

Showering can reduce enteric disease spread in orogenital practices, and douching may be protective for women. Petroleum-based lubricants (e.g., Vaseline petroleum jelly) retain organisms longer than water-based lubricants (e.g., K-Y lubricating jelly), and the use of petroleum-based products must be discouraged.

Men often practice rectal douching after anal intercourse, thinking that this cleansing procedure will decrease their risk of hepatitis B. The damage done to the rectum during anal sex is actually compounded by douching, and the risk of hepatitis B and HIV infection is increased. Hydrogen peroxide gargles and male urination after a sexual act have not been proved to decrease the risk of disease. These are common myths and need to be revealed as such.[7]

TABLE 3

How to Use a Condom

Before the need arises
1. Decide not to have sex unless a condom is used.
2. Discuss condom use with partner before becoming aroused.
3. Use latex condoms, water-soluble lubricants and nonoxynol-9, if tolerated.
4. Practice condom placement in advance.
5. Keep condoms in a readily accessible place.

Condom use
1. Pinch end of condom before putting it on, to allow a reservoir for sperm.
2. Place nonoxynol-9 inside the condom.
3. Unroll the condom fully onto erect penis.
4. Hold condom at base of penis on withdrawal.
5. Withdraw penis before erection subsides.
6. Use a new condom for each act of intercourse.
7. Never use a condom twice.
8. Never use petroleum-based lubricants with a condom.

Adapted from Sande MA, Volberding PA, eds. The medical management of AIDS. Philadelphia: Saunders, 1988:33.

SEXUAL PRACTICE COUNSELING

After the sexual history is completed, it is wise to summarize what the patient said to be sure both the physician and the patient understand what was said. One of the reasons a thorough sexual history should be taken is to enable the physician to counsel the patient about his or her sexual practices and suggest how they can be altered to reduce the risk of HIV exposure. Guidelines on sexual practices and HIV exposure are presented in *Table 4*.[12] Counseling can be provided throughout the interview, as appropriate, or at the end of the interview.

Importance of Drug Use History

The prevalence of HIV seropositivity among intravenous drug users varies greatly with geographic location. It is estimated to be as high as 61 percent in New York City and as low as 2 percent in San Antonio. In comparison, inner-city Baltimore reports 26 percent; Denver, 5 percent, and southern California, 4.5 percent.[13] HIV seroprevalence is 14 times greater among blacks who use intravenous drugs than among whites. Needle sharing is extremely common among intravenous drug users; 70 to 99 percent report sharing needles.[13]

Unfortunately, intravenous drug users have many misconceptions about HIV in-

best copy available

fection. Many of them consider acquired immunodeficiency syndrome (AIDS) a homosexual disease and thus not a threat to their health.[9] The long latency period between HIV infection and actual manifestations of the disease encourages complacency. Moreover, symptoms like those of HIV infection (e.g., weight loss, fever, lymphadenopathy, diarrhea, night sweats) are common in intravenous drug users who are not HIV-positive; therefore, many drug users do not consider the possibility that such symptoms may be related to HIV infection.[14] Nonwhites regard AIDS as a "white disease," although among intravenous drug users, minorities have a higher prevalence of HIV infection. Many intravenous drug users believe that it is safe to share a needle with someone they know or with someone who looks healthy. More than 75 percent of the time, needles are shared among relatives or close friends.[9]

TABLE 4

Guidelines on Sexual Practices and AIDS

Safe
- Body massage
- Hugging
- Body rubbing
- Mutual masturbation
- Social (dry) kissing
- Using one's own sex toys

Possibly safe
- Anogenital-receptive contact with condom
- Orogenital-receptive contact before ejaculation
- French (wet) kissing
- External urine contact
- Penile-vaginal contact with condom
- Orovaginal contact

Unsafe
- Anogenital-receptive contact without condom
- Anogenital-insertive contact without condom
- Anomanual contact
- Anodigital contact
- Orogenital-receptive contact with ejaculation
- Oroanal contact
- Anal or oral contact with urine
- Penile-vaginal contact without condom
- Sharing dildos, sex toys

Adapted from Campbell JM. Safe sex guidelines for risk reduction. In: Campbell JM, Warner WL, eds. Medical evaluation of persons at risk of acquired immunodeficiency syndrome. San Francisco: San Francisco AIDS Foundation, 1985:32-40.

In the homosexual community, participation in high-risk behavior is declining.[15] This is not the case among drug users. It is a common misconception in the medical profession that intravenous drug users cannot or will not change their behavior, but several studies have shown that they can. Intravenous drug users in New York City sought new needles because of their awareness of the increased transmission of AIDS from sharing needles.[14] In 1985, when public awareness of AIDS began to gain momentum, only 6 percent of intravenous drug users in San Francisco sterilized their needles. After an educational campaign was launched in which drug users were supplied with 15,000 vials of bleach and simple sterilizing instructions, 47 percent of users sterilized their needles.[9]

OBTAINING A DRUG USE HISTORY

The physician's attitude is most important in obtaining an accurate drug history. The physician must not be judgmental or moralistic. "You don't shoot drugs, do you?" is not a good way to obtain a drug history. Because intravenous drug use is illegal throughout the United States, patients are often reluctant to be truthful unless they trust the interviewer. It is helpful to start with less threatening questions, such as "What prescription drugs are you taking?" and "What over-the-counter drugs are you taking?" This is also the appropriate time to ask about alcohol and tobacco use. Some element of trust has now been established, and the physician can ask about marijuana and other illicit drug use.[16] "Have you used drugs bought from or given to you by a nonmedical source?" is more direct and less threatening than asking about "street drugs" or "illegal drugs." Finally, it is important to ask whether the patient has ever injected drugs intravenously.

As mentioned earlier, the physician should never assume anything. Many people who are not addicted to drugs will occasionally experiment with drugs.[17] Casual, social or recreational use of intravenous drugs—even once—can result in HIV exposure. Any patient, at any age, may have a history of illicit drug use.

The physician should look for other clues in the history or the physical examination that may be suggestive of drug use. In addition to the presence of needle tracks, a history of antisocial behavior, recurrent criminal arrests, or work or school failure may represent possible drug use. It may be helpful to use exploratory questions, especially with teenagers. Examples include "How easy is it to get drugs?" "Do you know people on drugs?" and "What happens at parties?" Such questions may open the door to further communication.[16]

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If there is a positive history of intravenous drug use, the physician needs more information from the patient. It is important to determine the number of persons with whom the patient has shared needles, syringes and drug vials, since any part of the equipment can be contaminated. The more persons with whom the patient has shared equipment, the higher the risk of HIV exposure. If the patient has shared equipment with nonwhites, he or she is at much greater risk of HIV exposure.

The places in which intravenous drugs have been used are also important: the East Coast presents a much greater risk of HIV exposure than the West Coast. "Shooting galleries," where addicts gather to purchase and inject drugs with used or shared paraphernalia, are areas of extremely high risk and are more common on the East Coast.[18] The physician must ascertain if the patient has attempted to sterilize needles, because the use of a 10 percent household bleach solution for one minute will inactivate HIV.[16] If the patient claims to use new needles only, the physician must realize that the "new" needles sold to drug users may actually be recycled ones.

COUNSELING DRUG USERS

Risk reduction issues that should be addressed when counseling drug users are presented in *Table 5*. Intravenous drug users are a major source of transmission of the HIV virus to the heterosexual community, especially in poor, urban areas.[17] About 75 percent of children born with HIV infection have contracted the virus from a drug-using parent.[9] In addition to being counseled about their drug use practices, intravenous drug users must also be encouraged to practice "safe sex" techniques, as previously discussed.

TABLE 5

Counseling on Preventive Measures for Intravenous Drug Users

Do not use drugs.
If using drugs, get treatment.
Do not share needles and equipment.
Clean needles and equipment
  (soaking items in 10 percent household bleach solution for 1 minute kills HIV).
Clean skin before injecting.
Avoid shooting galleries.
Practice "safe sex" techniques.

Adapted from Sande MA, Volberding PA, eds. The medical management of AIDS. Philadelphia: Saunders, 1988:34.

Final Comment

Through in-depth history taking and appropriate counseling, the medical profession has the opportunity to reduce the number of people who will contract the HIV virus. It is imperative that physicians ask all adult and adolescent patients about their risks of HIV exposure. Inquiring about high-risk sexual behavior and sharing of drug paraphernalia, followed by counseling on safer practices, is a worthwhile effort in controlling the HIV epidemic.

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THE FACTS ABOUT NEGOTIATING

Win-win negotiating means that instead of dominating, outsmarting or tricking the other person, you honestly work out problems together to arrive at a situation where both can win in the situation. How?

Three Fundamental Rules

1. If you narrow the negotiation down to one particular issue, then yes, it will become a win-lose situation. Instead, you must know that there are always a number of elements. Win-win negotiating is the art of piecing together the elements. Never absolutely narrow it down to one issue.

2. People don't want the same thing. Many people assume that others want what we want. Not true! Each of us has a unique perspective. The assumption that they want what you want can never lead to a win-win situation. There is no right and wrong side, just different perspectives. Learn not to fall into this trap.

3. While you're ultimately working toward a "yes", what does "no" mean? To a good negotiator, "No" is simply an opening negotiating position. Next time you make a proposal to someone, and they say to you, "That's the most ridiculous idea I've ever heard! You must be out of your mind to think I'd go along with something as incredible as that." Simply say to yourself, "Isn't that an interesting opening negotiating position."

THREE STAGES OF EVERY NEGOTIATION

1. Establish criteria:

   *Find out exactly what the other side wants to do, even when you're fairly sure you won't like what you're about to hear. It might just be something you can give them. Sometimes you're surprised when you narrow it down to find out exactly what it is they want.

   *Create your criteria in their minds. Tell them exactly what you are prepared to do, and ascertain how far you might be apart in the negotiations.

2. Get information: Find out exactly all you can about the other side. Don't jump to conclusions about the other side...ask for information.

3. Reach for compromises: Start looking for things that they might see of value that you're willing to concede in the negotiation, because they're not necessarily of value to you, and vice versa.

WHAT DOES IT TAKE TO BECOME A GOOD NEGOTIATOR?

1. The understanding that negotiating is always a two-way affair. The pressure is always on the other person to compromise in the negotiation just as much as it is on you. A good negotiator learns to mentally compensate for the fact that we always think we have the weaker side in the negotiation.

2. The desire to acquire the skills of negotiating. Negotiating is not just for union leaders, FBI agents and prison wardens. Everyone is negotiating all the time!

3. The understanding of how the different negotiating principles work.

4. The willingness to practice. You don't have to wait until a heavy negotiating situation before you work with these skills. Learn to practice in little areas too.

5. The desire to create win-win solutions.

AN EFFECTIVE MODEL FOR WIN/WIN NEGOTIATIONS

C Clarify Intentions
O Options. . . Explore them!
R Reach Agreement
E Enjoy or Exit Negotiation and Try Again Later

1. Clarify both your own and your partner's intentions.

   a. Know what you want.

   b. Don't assume your partner wants the same thing you do.

   c. Be the first to bring it up with partner; take a risk. He or she may be relieved or unhappy that you brought it up. Either way, you're being true to your sense of responsibility and healthy sexuality.

   d. The hardest part may be to communicate about one's own desires and choices regarding safer sex. Understand that not only is it difficult for you to communicate your desires, it may also be difficult for your partner.

   e. You must practice communicating what you want!

2. Options: explore them!

   a. Don't narrow the negotiation to a single sexual behavior. Explore all possible alternatives!

   b. Refer back to the continuum and remind participants of the alternatives available.

3. Reach Agreement

   At this point you have clarified your intentions and explored your options. You'll either reach agreement, or you may agree to disagree.

4. Enjoy or Exit

   a. If agreement is reached, ENJOY.

   b. If not, this is a good time to EXIT and try negotiation again later.

** Adaption of concepts taken from an audio-cassette program, "You Can Get Anything You Want ... The Secrets of Power Negotiating," by Roger Dawson, who is a world recognized authority on the art of negotiating, and a nationally known speaker and business consultant.

HOW TO TALK ABOUT CONDOMS WITH A RESISTANT ,DEFENSIVE, OR MANIPULATIVE PARTNER

If the partner says:	You can say:
"I'm on the Pill you don't need a condom.	"I'd like to use it anyway. We'll both be protected from infections we may not realize we have."
"I know I'm clean (disease-free); I haven't had sex with anyone in X months.	"Thanks for telling me. As far as I know, I'm disease-free, too. But I'd still like to use a condom since either of us could have an infection and not know it."
"I'm a virgin."	"I'm not. This way we'll both be protected."
"I can't feel a thing when I wear a condom; it's like wearing a raincoat in the shower.	"Even if you lose some sensation you'll still have plenty left."
"I'll lose my erection by the time I stop and put it on."	"I'll help you put it on-that'll help you keep it."
"By the time you put it on, I'm out of the mood."	"Maybe so, but we feel strongly enough for each other to stay in the mood."
"It destroys the romantic atmosphere."	"It doesn't have to be that way."
"Condoms are unnatural, fake, a total turnoff."	"Please let's try to work this out - an infection isn't so great either. so let's give the condom a try. Or maybe we can look for alternatives."
"What kinds of alternatives?"	"Maybe we'll just pet, or postpone sex for awhile."
"This is an insult! Do you think I'm some sort of disease-ridden slut (gigolo)?"	"I didn't say or imply that, I care for you but in my opinion, it's best to use a condom."

"None of my other boyfriends uses a condom. A real man isn't afraid."	"Please don't compare me to them. A real man cares about the woman he dates, himself, and about their relationship."
"I love you! Would I give you an infection?"	"Not intentionally. But many people don't know they're infected. That's why this is best for both of us right now."
"Just this once."	"Once is all it takes."
"I don't have a condom with me."	"I do," or "Then let's satisfy each other without intercourse."
"You carry a condom around with you?" "You were planning to seduce me!"	"I always carry one with me because I care about myself. I have one tonight because I care about us both."
"I won't have sex with you if you're going to use a condom."	"So let's put it off until we can agree." or "OK, then let's try some other things besides intercourse."

SPECIAL INSTRUCTIONS FOR INDIVIDUALS POSITIVE FOR THE HIV/AIDS ANTIBODY

PERSONS WITHOUT SYMPTOMS, PERSONS WITH AIDS RELATED COMPLEX AND PERSONS WITH AIDS

I. WHAT DOES IT MEAN IF YOU HAVE THE ANTIBODIES TO THE HIV VIRUS THAT CAUSES AIDS?

Antibodies are substances produced in the blood to fight organisms. When antibodies to a specific organism are found in a person's blood, they indicate that the person has been infected by that particular organism.

If your test for AIDS antibody is positive, it usually means that you have been infected by the HIV (or AIDS) virus, and that you can transmit it to others, even if you show no symptoms.

II. HOW DOES THE VIRUS AFFECT THE BODY?

Infection with the AIDS virus can take several forms. In each form an infected person can transmit the virus to others.

* AIDS Carrier (Positive HIV Test With No Symptoms): Many people carrying the AIDS virus do not get sick for a long time, and some may never get sick. The only sign of an AIDS infection in these people may be a positive blood test for antibodies to the AIDS virus.

* ARC (AIDS Related Complex): ARC is a condition caused by the AIDS virus in which the patient tests positive for HIV infection and has a specific set of clinical symptoms. However, ARC patient's symptoms are often less severe than those with the disease we call AIDS. Signs and symptoms of ARC may include loss of appetite, weight loss, fever, night sweats, skin rashes, diarrhea, tiredness, lack of resistance to infection, or swollen lymph nodes. Even though the symptoms may be relatively mild, they can be persistent, and may even be debilitating and even fatal.

* AIDS: Some persons with the HIV infection develop full-blown AIDS, which may appear years after initial infection, whether or not ARC occurs. AIDS destroys the body's immune (defense) system and allows otherwise controllable infections to invade the body and cause additional diseases: persistent cough and fever associated with shortness of breath or difficult

breathing which may be symptoms of Pneumocystis carinii pneumonia; multiple purplish blotches and bumps on the skin which may be a sign of Kaposi's Sarcoma, a form of skin cancer; and central nervous system signs such as weakness on one side of the body, seizures and impaired vision.

III. HOW CAN I PROTECT OTHERS FROM GETTING THE AIDS VIRUS?

All persons HIV positive to the AIDs virus (all those in the above categories) should follow the same precautions against spreading the virus.

AIDS is NOT spread by day-to-day contact such as being near, touching, or eating with a person with AIDS.

However, certain activities have been proven to spread the virus. Therefore, the following steps should be taken:

* Be sure to tell your sex partners about your positive test result. Avoiding sex would eliminate any risk of spreading the virus by sexual means; however, if you and your partner decide to go ahead, be careful to protect him or her from contact with your body fluids, which may carry the AIDS virus. ("Body fluids" includes blood, semen, urine, feces, saliva, and vaginal secretions.)

* Vaginal sex:Always use a condom (latex only) or a condom and a diaphragm and a spermicide containing nonoxynol-9. Research shows that condoms, when properly used, help stop the virus that causes AIDS. Follow the directions given on the package to be sure that the condom does not break. Remove and dispose of it carefully. Never re-use a condom!

* Lubricants:Sexual lubricants must be water soluble. DON'T use vaseline, Crisco, mineral or vegetable oil. These make the condoms break more rapidly.

* Oral sex:If the man is infected, his semen should not enter his partner's mouth. If the woman is infected, vaginal secretions could carry the virus. Blood, which is contained in menstrual fluid, has been proven to carry the virus. Oral sex with an infected woman is probably most risky during menstruation.

* Anal sex:Avoid practices, such as anal intercourse, that may injure body tissues and make it easier for the virus to enter the bloodstream.

* Kissing:Kisses on the skin are completely safe. And although the AIDS virus has been found in tiny amounts in most body fluids, including saliva, there are no known cases of AIDS transmission via mouth-to-mouth kissing.

However, it is recommended that open-mouth and intimate kissing should be avoided.

* Don't donate blood or plasma, body organs, other body tissue, or sperm.

* AIDS may also be passed from a mother to an unborn child during pregnancy or at birth.

****** People who have been your sex partners may have been exposed to the AIDS virus. If you have used intravenous drugs, anyone you have shared needles and syringes with may have been exposed to the AIDS virus. You should tell these persons about your positive test result and urge them to seek counseling and antibody testing from a doctor or health clinic.

IV. HOW CAN I PROTECT MYSELF FROM INFECTIONS?

Because of the body's weakened immune defense system, special care should be taken to protect yourself from potentially harmful bacteria, protozoa, fungi, and other viruses which may cause life-threatening illnesses.

* You should be careful to follow the normal practices everyone needs to maintain good health: Eat a well-balanced diet, exercise, rest, and try to manage your life in a way that avoids undue stress.

* Maintaining a state of personal cleanliness is helpful to both the person with HIV infection and others. This includes bathing regularly, washing hands after the use of bathroom facilities or contact with one's own body fluids such as semen, mucus, or blood, and washing hands before preparing food.

* Kitchen and bathroom facilities may be shared with others. Normal sanitary practices in any household will prevent the growth of fungi and bacteria that may potentially cause illness in both immunocompromised and immunocompetent people. These include:

* Clean kitchen counters to remove food particles. Scouring powder is not recommended, since it is an abrasive and with repeated daily use may cause small scratches which could harbor microorganisms. Sponges used to clean in the kitchen where food is prepared should NOT be the same sponges used to clean up bathroom-type spills. Dirty looking sponges should not be used to wash dishes or clean food preparation areas.

* Clean inside of refrigerator with soap and water to control mold formation.

* Mop kitchen floor at least once a week. Bleach 1:10 strength (1 part bleach to 9 parts water) can be used to disinfect the sink, floor and shower floor (athletes foot is caused by a fungus which bleach will kill). A little full strength bleach can be poured into the toilet bowl for disinfection. Any spills of body fluids or waste (blood, urine, stool, vomitus, etc.) should be cleaned up first and then the surface disinfected with 1:10 bleach.

* Sponges used to clean the floor of any body fluid spills SHOULD NOT BE USED TO WASH DISHES OR CLEAN FOOD PREPARATION AREAS. Mop water should NOT be poured down sink where food is prepared. Sponges used to clean up spills should not be washed out at sinks where food preparation occurs. Sponges and mops can be disinfected by soaking in 1:10 bleach for 5 minutes (longer may disintegrate sponge).

* Dishes may be shared with others provided they are washed in hot soapy water (hot enough to require gloves). A disinfectant does not need to be used.

* Since unpasteurized milk and milk products have been associated with Salmonella infections in the past, these should not be included in the diet. Salmonella infections are not well tolerated by people with HIV infection.

* If organically grown food is used (composed with human or animal feces), food should be cooked or be fruits that can be peeled. "Organic" lettuce is not safe.

* Towels and wash cloths should not be shared without laundering in between people. Toothbrushes, razors, enema equipment and sexual toys should not be shared.

* Trash disposal should be the same as for any household. Body wastes are flushed down the toilet. Other trash may be adequately handled by normal means (weekly trash pickups from cans lined with a plastic bag and a tight fitting lid to keep out rodents). In the event of large amounts of sputum, wound drainage, etc., on kleenex or dressings, it is a good idea to collect them in a lined trash can in the house.

* Pets - gloves should be used when cleaning bird cages (Psittacosis) and cat litter boxes (Toxoplasmosis). Tropical fish tanks may contain organisms in the Mycobacterium family which are not well tolerated by persons with HIV infection. Get someone else to clean your tank.

* Keep living quarters well ventilated. Airborne diseases are less likely to be a problem when diluted by lots of air.

* Persons with HIV infection who are coughing should cover their mouths with tissues or handkerchiefs.

Persons with HIV infections living together can do so safely by observing the same common sense hygiene practices discussed above. The opportunistic infections acquired by persons with HIV infection are caused by organisms commonly found in the environment. The risk of becoming sick from one of these infections is based on the amount of immune system impairment, not on casual household contact.

V. DISINFECTION PROCEDURE FOR CONTACT WITH VIRUS-BEARING FLUIDS:

* Open cuts or wounds exposed to virus-bearing fluids: Wash exposed surface with either a solution of 3 percent hydrogen peroxide in water or a solution of 10 percent household bleach (such as Clorox) in water.

* Skin not open or lacerated: Wash exposed surface with either 70 percent (or higher) solution of either ethyl or isopropyl alcohol or a solution of 3 percent hydrogen peroxide.

VI. MORE INFORMATION CAN BE OBTAINED FROM:

* Your Doctor or Nurse: Miami VA Medical Center, #324-3267, or #324-4455 and have the operator beep #386.

* The Public Health Service's toll-free hotline: 1-800-342-AIDS.

* Health Crisis Network's hotline, group and individual counseling and support groups: #634-4636.

- Prepared by Grace Lusby, MS, RN, Infection Control Coordinator,San Francisco General Hospital and Helen Schietinger, MA, RN,Director, Shanti AIDS Residence Program.

- Reprint permission from Gay Men's Health Crisis, Department of Education granted to Health Crisis Network, Inc., P.O. Box 52-2546, Miami, Florida, 33152.

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ADAPTED FROM AIDS HEALTH PROJECT, SAN FRANCISCO, CA

Special Populations

While the preceding guidelines offer a general structure for the disclosure of antibody test results, the unique psychosocial issues of differing populations must be given special consideration when counseling women, people of color, gay and bisexual men, and IV-drug users. A summary of these issues follows.

A. Women

A woman's decision to seek AIDS antibody testing is frequently motivated by pregnancy or family planning concerns. As such, the counselor should question whether the client is currently pregnant, considering pregnancy, or has young children at home.

In addition to the general outline of issues presented earlier, the counselor needs to be familiar with the special needs of women and AIDS virus infection. The psychosocial issues confronting a seropositive woman may be unique in several aspects. First, it is possible that the positive test result may have an impact on an entire family rather than just a single individual. If the woman is pregnant or has small children at home, she may experience tremendous guilt and worry that her offspring may also be infected. Women who are pregnant are faced with the difficult question of whether or not to terminate the pregnancy because of the risk that her child will be born seropositive. Others are faced with the loss of the opportunity to conceive a child.

Second, women may have special challenges in following safer sex practices. Women frequently report difficulty in engaging their male partners' cooperation, e.g., the partner refuses to use a condom. This may be partially attributable to a general lack of awareness and knowledge of AIDS transmission in the heterosexual community. These difficulties may also be partly due to overt or internalized sexism which manifests as a woman's reluctance to assert her desire and set limits with her partner and the male partner's demand that the woman remain passive.

Third, the seropositive woman may also feel especially isolated and alone. Again, lack of AIDS awareness or understanding in the heterosexual community may contribute to this isolation. Many women will not have a social support system outside of their immediate family and may be reluctant or unable to obtain the emotional support they need from the family. For this reason, referrals to appropriate agencies for social and emotional support is as integral an intervention as referral to family

However, AIDS related social services and support groups specifically targeting women may not be available in many communities and, unfortunately, further isolate seropositive women.

It is important to emphasize that over 70 percent of all women with AIDS are Black or Latina and the majority are from poor backgrounds. This breakdown will most likely also be reflected in the numbers of seropositive women. Consequently, counseling and referrals must address the specific needs and concerns of these women.

B. People of Color

Due to the widespread misconception that AIDS is a disease of white gay men, many people of color may not fully realize their degree of risk for being infected with the AIDS virus, although they account for 40 percent of AIDS cases nationally. Lack of concerted AIDS outreach, educational efforts, and services in the Black, Latino, Asian and Native American communities may foster a false sense of security among many people of color. There exists in these communities a sexual fluidity and culturally-based denial of homosexual behavior, e.g., a married man has sexual relationships with other men and doesn't consider himself gay or bisexual. Private acknowledgement of homosexuality may occur within the family, but public acknowledgement does not always follow. As such, the counselor should emphasize the concepts of risk behavior as opposed to membership in risk groups or attachment to specific labels or identification.

IV drug use as a mode of AIDS transmission within the Black and Latino communities is disproportionately high. Blacks and Latinos account for over 80 percent of AIDS cases with IV drug use as the primary risk factor. The strong legal and social prohibition against the use of IV drugs may cause current users to not openly and honestly discuss their practices. Therefore, it is extremely important for the counselor to always include discussion of the dangers of sharing needles and the methods of cleaning needles before each use, in addition to discussion of safer sex practices.

For immigrants, the possibility of testing positive poses a threat of deportation and family separation. The counselor should assure that the individual understands this as a possible outcome. Immigrants are particularly isolated and distrustful of authorities due to either cultural or language barriers or their illegal status in this country. It is extremely important to be sensitive to their position and identify health care resources and social service agencies targeting the specific immigrant group.

Culturally-influenced responses to persons in authority, i.e., the counselor or health care provider, might include mistrust of or extreme deference to the authority figure. A counselor's lack of sensitivity to these potential dynamics might inhibit the client's willingness to openly discuss his or her personal situation.

Finally, cultural and religious views on sex frequently pose difficulties in advising clients on safer sex practices. Many clients may not feel comfortable discussing their sexual practices. Cultural emphasis on the importance of having a family or religious beliefs which preclude sex for purposes other than procreation may present clients with a significant moral dilemma when confronted with the need to use condoms and follow safer sex practices. Referral to community resources which are both AIDS-sensitive and culturally and/or religiously affiliated can provide the client with the opportunity to receive support and guidance while working through these issues.

C. Gay and Bisexual Men

While the gay and bisexual male communities have wrestled with the specter of AIDS since the beginning of this crisis, the psychosocial issues of this population remain unique in several respects. Society's open discrimination and stigmatization of these individuals fosters internalized homophobia (a fear or hatred of homosexual feelings). AIDS has caused internalized homophobia feelings in many gay or bisexual men to intensify. Expression of this internalized homophobia may take the form of depression, a sense of guilt and self-blame, or decreased motivation to take precautionary or health-promoting behaviors due to a sense of "deserving to be punished" for one's sexual identity.

As the self-image of gay and bisexual men has been closely tied to the sexual behaviors which sets them apart from the majority of individuals, the need to change such behaviors may represent a significant loss. Underscoring the client's ability to maintain his affectional preferences while practicing safer behaviors is an important counseling strategy in addressing this sense of loss. Assisting the client in identifying his other unique personality traits and talents may also lessen the perceived threat to self-image.

Though the gay community has demonstrated a strong presence in many large metropolitan areas, gay and bisexual men are often extremely isolated and lack adequate social and emotional support. Many gay and bisexual men have carefully hidden this behavior for fear of rejection by family and friends or loss of employment or housing. This may be particularly true in rural areas. Even individuals who have experienced a strong social support in the past may have experienced a significant loss of this support due to the death of friends and lovers to AIDS.

In addition, a disproportionate number of gay and bisexual men abuse alcohol and/or other recreational drugs. As such, exploration of substance use and its relationship to high-risk behaviors and impairing overall immune functioning should be an integral part of the counseling session.

D. I.V. Drug Users

Given the strong legal and social prohibition against the use of IV drugs, users will most likely be reticent to openly and honestly discuss their needle use with a counselor. These clients must be offered repeated and very real assurances that any disclosure to the counselor will not have negative consequences for the client. Even with such assurances, many IV drug users will fail to disclose this risk behavior during counseling sessions. Thus, every counseling session should include a thorough discussion of the dangers of sharing needles and the methods of cleaning needles before each use, in addition to discussion of safer sex practices.

Denial is a well-established coping mechanism for the IV drug user. Denial of the negative consequences of drug use allows the individual to continue this behavior in spite of the often dramatic problems drug use has caused in the individual's life. Such denial is likely to be the user's response to AIDS education efforts, partially fueled by the convenient myth that the virus affects only white gay men. The counselor must unequivocally and repeatedly confront this denial with simply stated facts on the prevalence of the virus in the IV drug- using community and the behaviors which transmit the disease. The counselor must be reminded that it is not his/her role to deal with issue of addiction, per se, but to promote and encourage the adoption of AIDS risk reduction behaviors.

Additionally, many IV drug users have little social support. Many are isolated and alone, frequently rejected by family and friends. Often any social contact that does occur revolves around drug procurement and use. Referrals to resources which can actively support and encourage the clients' contact with appropriate substance abuse agencies should be made. Immediately contacting such agencies is often an important intervention for these clients.

E. Follow-up

Follow-up sessions can be useful for different reasons. The disclosure session is usually emotion-laden and too brief for the client to remember every important detail. Experience has shown that some individuals (especially those who received positive test results) barely remember the content of the session because of the strong emotional reactions engendered during the interview.

Receiving a test result is a first step in a long process. Since seropositives are thought to be infectious for life, further help may be needed to establish and maintain necessary changes, especially for those who experience emotional difficulty after receiving their result. Frequently, clients have reported prolonged depression and feelings of isolation and stigmatization, impotence, and panic or anxiety disorders. While occurring in some individuals, most clients (even those with positive test results) make a satisfactory adjustment to their situation. Providing a support group has been shown to be extremely helpful for some test recipients. Also, personnel in already existing community services should be trained to provide follow-up services.

It is unknown which seropositive test recipients will go on to develop AIDS or ARC, although current statistics from studies indicate that the majority of individuals infected with the AIDS virus will most likely develop AIDS or ARC over time. Medical follow-up should be established for continuity of care as well as evaluation of treatable diseases or infections with AIDS-knowledgeable and -sensitive physicians and clinics. Such follow-up is particularly important for pregnant women or seropositive women and their children. If an individual does develop AIDS or ARC, appropriate medical and social services can then be provided.

AIDS and Minorities

Why is it necessary to address the issue of AIDS in racial and ethnic minorities separately from AIDS in any other population? The fact is that a greater percentage of Blacks and Hispanics are becoming infected with HIV than are Whites in the United States. In this country, according to 1980 census figures, Blacks make up 11.5% of the population. However, they make up a much larger proportion of persons with AIDS: 24%. The same is true for Hispanic people, who constitute only 7% of the nation's population, but make up 14% of people with AIDS. Blacks and Hispanics make up only one-third of people with AIDS; however, AIDS is spreading at a faster rate and to a higher percentage of these population groups than to Whites.

Earlier in the AIDS epidemic, some felt that Asians/Pacific Islanders were immune to HIV because there were few reported cases of AIDS among this population. According to the 1980 census, Asian/Pacific Islanders make up 1.6% of the population in this country. AIDS cases among Asian/PI's constitute 0.6% of all AIDS cases. This number will grow unless the population perceives that AIDS poses a health threat to them and takes the necessary precautions against infection.

The data for AIDS cases among American Indian/Alaskan Natives are underreported because of the difficulty of identifying members of this group when they live or receive medical care or counseling outside a reservation or areas where American Indians live in large groups. We do know that some Native American tribes are represented by a few hundred people or less. Even one infected person in this group could represent a serious threat to the entire group.

In 1980 American Indians represented less than 1% of the U.S. population. The percentage of all AIDS cases that are American Indian/Alaskan Native is 0.1%. Because of high rates of sexually transmitted disease and substance abuse, American Indians and Alaskan Natives are particularly at risk for HIV infection. The overall number of reported diagnosed cases of AIDS is still low in this population, but growing.

Reproduced from poor document.

Special emphasis needs to be placed on providing information to these groups about preventing HIV transmission. From research that tells us who and where the people are who are at risk, we will know how and where to focus prevention efforts.

As of May 9, 1988, there were a total of 61,596 cases of AIDS reported in the United States. Over half of those have died of AIDS or AIDS-related causes. It is estimated that there are 1.0 to 1.5 million people in the United States who are infected with HIV. We do not yet know how many of those people will develop AIDS, but observation of a group of homosexual men in San Francisco showed that 48% developed AIDS over a 10-year period.

It is clear from data collected that transmission patterns do vary by race. In White males, HIV is spread mainly by sexual contact between homosexual men; only 4% of White adult men are known to have contracted HIV solely through IV drug use. For Black men with AIDS, however, one-third (34%) were infected through sharing of IV drug needles, and for Hispanic men, 36% became infected through IV drug use (see Figure 1).

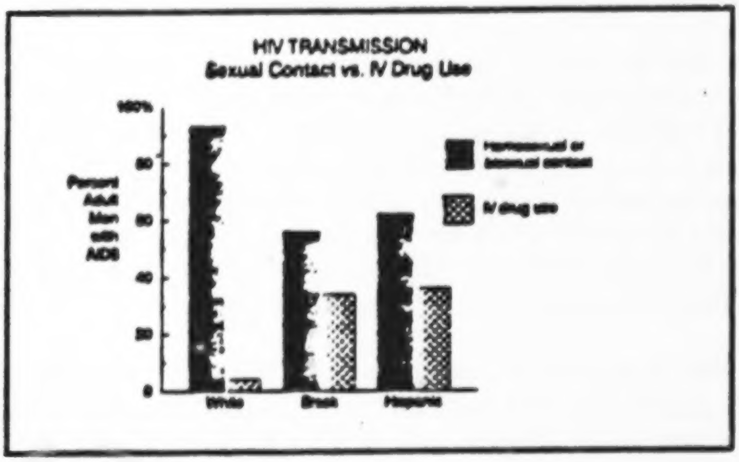

Figure 1. Percentage of adult men with AIDS who contracted the virus through homosexual/bisexual contact or through IV drug use.

This figure indicates that a higher percentage of minorities are becoming infected through sharing contaminated IV drug needles than are White men. This may be caused by a higher percentage of Blacks and Hispanics using IV drugs than Whites. Additional factors may also play a role. It may be that needle-sharing practices are more frequent among Blacks and Hispanics than among Whites. It has also been noted that some IV drug users who are Black or Hispanic tend to have a lower educational level than their White counterparts, and until recently, there were very few funds for outreach into these communities. Therefore, it is possible that Black and Hispanic IV drug users may not know the danger of HIV infection through needle-sharing.

It is clear that the minority drug-using population is as much in need of prevention efforts as are minority homosexual and bisexual men. However, the spread of HIV by male homosexual and bisexual activity continues to be the dominant source of transmission in all adult males, regardless of race or ethnic background, and it is important that these people understand the risk of exposure.

The problems associated with IV drug use and the differences in the social and cultural expression of sexuality, illness and death among minority groups may give some clues as to why AIDS is spreading at a higher rate in some minority groups. The IV drug-using population is difficult to pinpoint and reach with educational programs. Additionally, their behavior usually involves addiction, and therefore is hard to change. They often have complicating physical conditions such as infections (for example, hepatitis B), and access to health care for this group is often difficult.

In addition, attitudes toward homosexuality among the minority groups make it difficult to reach this group with appropriate educational messages. Nearly 60% of Blacks and Hispanics with AIDS were infected through homosexual/bisexual contact (Figure 1). However, definitions or perceptions of homosexuality or bisexuality may differ among these groups. For example, a man who has sex with a man in prison or a man who is in the dominant position may not be considered homosexual.

The White homosexual population has been mobilized and is now a more accessible target for comprehensive AIDS education, and, as a result, several studies suggest that the rate of new HIV infection in that group in some areas is on a steady decline. But this is not so for IV drug using populations or homosexual minority men.

If we compare data from the year May 9, 1986 - May 9, 1987 with May 9, 1987 - May 9, 1988, we can see that the percentage of men with AIDS of all races/ethnic groups who became infected through homosexual or bisexual contact has gone down, while the percentage of men who became infected through IV drug use has gone up (Figure 2). Because we cannot determine exactly when these men became infected, these data indicate trends rather than changes that are specific to a certain time period.

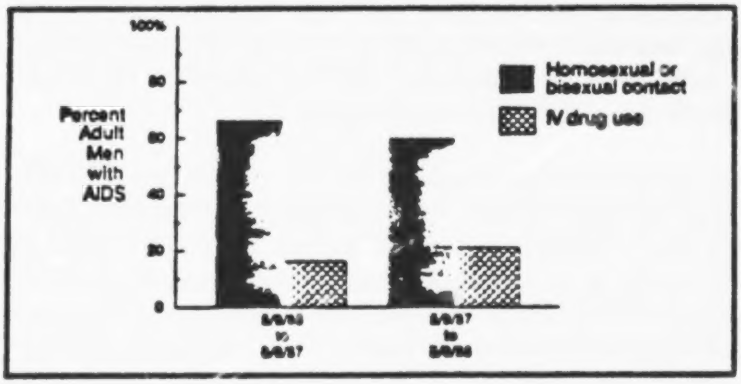

Figure 2. Changes in the percentage of adult men with AIDS contracted through sexual contact or IV drug use.

Because HIV infection in Whites is mainly found in the male homosexual population, it has not spread rapidly to the White heterosexual population. That has not been the case with Blacks and Hispanics, who are more likely than Whites to have become infected with HIV by sharing IV needles. These persons have often transmitted the virus to their heterosexual partners. Since there is a high rate of HIV infection in minority drug users, it follows that there is a high rate of AIDS in their heterosexual partners. Black and Hispanic women account for almost 70% of adult women with AIDS (see Figure 3).

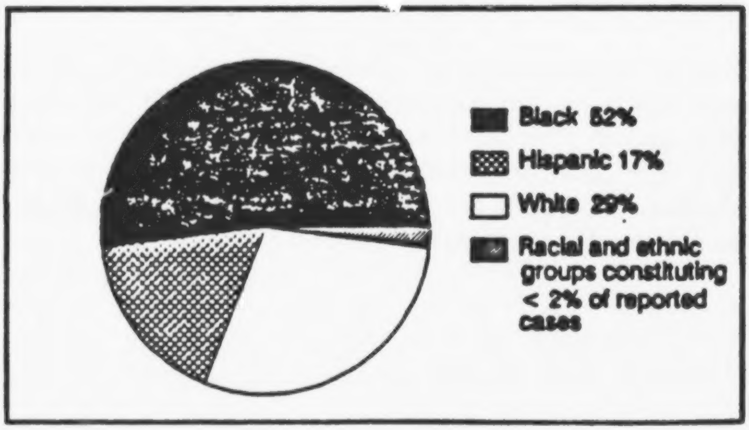

Figure 3. Adult women with AIDS by ethnic background. (as of March 11, 1988).

White women account for only 29%. Over 60% of minority women with AIDS have become infected through sharing contaminated needles. Over 30% became infected through heterosexual contact. Through these infected women, a very high number of minority children are becoming infected during birth.

Over half of the children with AIDS in the United States are Black (Figure 4). Black and Hispanic children together make up 74% of children with AIDS. Most of those minority children were infected in the womb or during birth. White children account for only 23% of children with AIDS, and over half of these children became infected by receiving a contaminated blood transfusion or blood product (Figure 5).

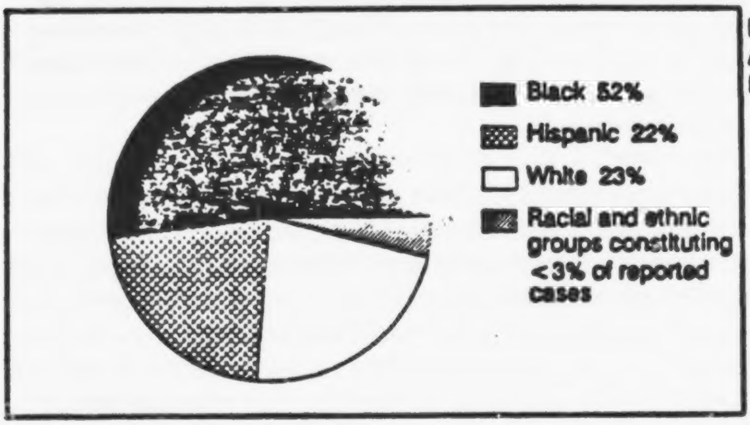

Figure 4. Children with AIDS by ethnic background.

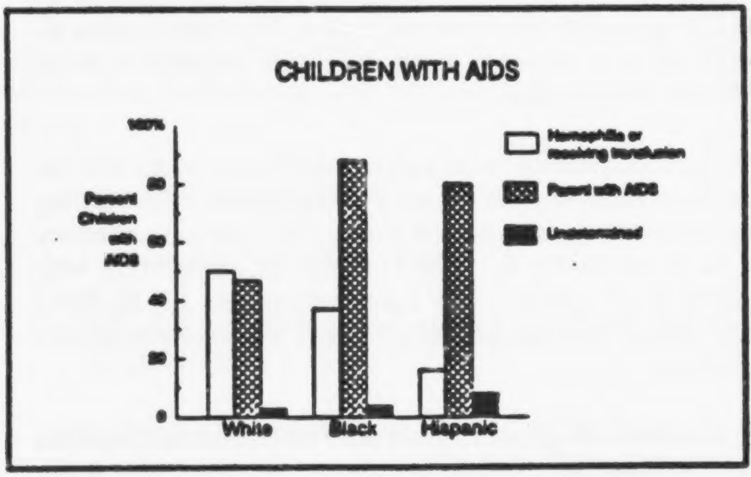

Figure 5. Children with AIDS by ethnic background and risk factors.

Since March 1985, all donated blood in the United States has been screened for HIV, so the rate of new infection by this route has practically reached zero.

It is imperative that all racial and ethnic minorities become involved in understanding the methods of transmission of HIV and the steps to prevent HIV infection and AIDS since there are people who engage in high-risk behavior in these communities.

There is currently no effective cure for AIDS, and there is no vaccine which will prevent infection with HIV. Scientists are working to make headway in both of these areas. There are, however, tests that together or in sequence will confirm whether or not a person is infected with HIV. At present, our only way to prevent the spread of AIDS is through preventing exposure to the virus. All known methods of transmission have been publicized, and the steps to prevent exposure have also been well defined.

1. Individuals should not have sex with infected persons. The more sexual partners a person has, the greater the chance of coming into contact with an infected person. Practicing abstinence or maintaining a relationship with just one person will protect a person from HIV infection, providing that the partner also remains faithful to the relationship and is free from HIV infection. If a person is in a relationship with an infected person, both parties should investigate methods of safer sex through counseling with their physician or an AIDS outreach education counselor. This may involve always using condoms or changing sexual behavior to avoid risky sexual practices.

2. Precautions should be taken to avoid direct contact with infectious fluids such as semen and vaginal secretions during sexual activity with a person whose HIV status is unknown. Use of condoms for 100% of sexual encounters with partners of unknown HIV status will reduce (by 80-90%) the risk of HIV transmission, but will not totally eliminate the risk.

3. Intravenous drug users should not share needles. If needles and syringes are reused, they should be thoroughly disinfected.

4. Women who are at high risk of being infected and who are pregnant or could become pregnant should get testing and counseling for HIV infection.

5. Persons who are HIV-infected or who may have exposed themselves to the virus should not donate blood, body organs, or other body fluids.

6. Infected and uninfected persons should not share razors, toothbrushes, or other items that might cause cuts or be contaminated with blood.

7. Health care workers should always be careful to follow the proper procedures in caring for all patients, whether the patient's HIV status is known or not.

These steps often involve changes in long-established behavior that may be hard to bring about.

The number of people diagnosed with HIV infection each year will continue to increase at least into the next decade. It is estimated that as many as 365,000 persons will have been diagnosed with AIDS in the United States by 1992. It is, therefore, crucial that we be able to identify those groups at risk, prevent new infections, and prepare to provide services to all who are ill.

Bibliography

There are many sources of excellent information on AIDS and HIV infection in general. You can find these sources by contacting

- your local medical society
- a nearby medical school library
- National AIDS Information Clearinghouse: 1-800-458-5231
- National AIDS Hotlines: 1-800-342-AIDS (English);
  1-800-344-SIDA (Spanish)

In addition, you may find the following helpful in understanding the problem of AIDS and minorities:

Bakeman R, McCray E, Lumb JR, et al. The incidence of AIDS among Blacks and Hispanics. *Journal of the National Medical Association* 1987;79(9):921-28.

Guinan, ME, Hardy A. Epidemiology of AIDS in women in the United States. *Journal of the American Medical Association* 1987;257(15):2039-2042.

Rogers MF, Williams WW. AIDS in Blacks and Hispanics: implications for prevention. *Issues in Science and Technology* 1987;III(3):89-94.

Schinazi RF, Nahmias AJ. *AIDS in children, adolescents and heterosexual adults: an interdisciplinary approach to prevention.* New York: Elsevier Science Publishing Co., 1988.

For the general population:

Centers for Disease Control. *AIDS: Recommendations and Guidelines, November 1982 - December 1987.* U.S. Government Printing Office: 1988-530-009/64831, April 1988.

Surgeon General's Report on Acquired Immune Deficiency Syndrome (pamphlet available by calling the National AIDS Hotline: 1-800-342-2437 or Spanish language hotline: 1-800-344-SIDA)

Understanding AIDS. HHS Publication No. (CDC) HHS-88-8404. (Available by calling the National AIDS Hotline: 1-800-342-2437. Spanish language version available through the Spanish language hotline: 1-800-344-SIDA)

EPIDEMIOLOGY OF HIV IN WOMEN: AN UPDATE

UNITED STATES

There were 9,346 women in the U.S. reported to have met the CDC surveillance case definition for AIDS (August, 1989).

Women with AIDS:

* Approximately 9% of adult AIDS cases are women
* Nearly 52% of these women are intravenous drug users
* 30% are sexual partners of men in risk groups (primarily heterosexual intravenous drug users)
* 10% have received infected blood or blood products
* 89% are between 20 and 49 years old
* 28% are white
* 72% of women with AIDS are of ethnic minorities
* 52% are black
* 19% are Latina/Hispanic
* 1% are other ethnic groups (including Asian and American Indians)

Although women with AIDS comprise only 9% of all AIDS cases, they provide a focal point for several reasons:

1) Women with AIDS are the major source of HIV infection of infants with AIDS.

2) Heterosexual intercourse is the second most common route (behind IV drug use) of AIDS transmission for women.

Trends in AIDS cases among women may help determine current and future trends among pediatric AIDS cases and heterosexual transmission of HIV infection.

For the most part, the geographic distribution of AIDS cases in women is similar to that in IV drug-using men. The highest number of cases in women were found in New York, followed by New Jersey, Florida, and California.

Excluding homosexual/bisexual men, the overall ratio of men with AIDS to women with AIDS is 3:1. The ratio was highest for hemophilia/coagulation disorder cases (33:1); and lowest (0.2:1) for heterosexual contact with a person at risk for AIDS (this is the only transmission category where women with AIDS outnumber men with AIDS). The proportion of women with AIDS has increased annually between 1982 and 1989. At present a heterosexual woman in the U.S. is at greater risk for acquiring AIDS than a heterosexual man. The larger number of AIDS cases acquired by heterosexual contact is likely to be the results of two factors:

*Based on a summary of aids in Women: AIDS/HIV Reference Guide for Medical Professionals, ed. D. Shin & J. Avers,Univ. of CA, 1988.

1)As a greater proportion of men are infected, the likelihood of female encountering an infected male partner is greater.

2)The efficiency of HIV transmission from an infected male to female may be greater than from an infected female to male. Among all women, intravenous drug use accounts for the majority (52%) of cases; heterosexual contact (with an infected man) accounts for 30% of cases; many of these contacts were with a man who used intravenous drugs. Transfusions account for infection in 10% of the cases, with 7% remaining under investigation--risk yet to be identified.

Tables 1
WOMEN WITH AIDS
TRANSMISSION CATEGORY AND RACE*

	% of AIDS cases who are Women	IV Drug User	Hetero-sexual contact	Transfusion or Hemophilia	Other
White	4	1,049	660	680	200
Black	17	2,807	1,486	194	361
Hispanic	11	955	634	99	119
Other	10	25	24	20	8

*As of August 1989 CDC HIV/AIDS Surveillance Report

The proportion of women with AIDS varies among the ethnic groups as well as the source of infection (See Table 1). Although IV drug use is the largest transmission category for all racial groups, it accounts for more than half of the cases of AIDS in blacks and Hispanic/Latina women. For white women and women of other ethnicities it accounts for less than half.

Minority women in the IV drug-using community (including those who use drugs as well as those whose sexual partners are IVDUs) are at particular risk from infection with the AIDS virus. These women account for more than half of the women with AIDS, as well as most of the transmission to children.

Receptive anal intercourse has been associated with an increased risk for AIDS and for HIV infection in homosexual men. Recently an association between anal intercourse and HIV infection among heterosexuals has been demonstrated. Examining female sexual contacts of men with AIDS, ARC, or seropositive for HIV within a year before diagnosis, the number of sexual contacts (vaginal, anal, or oral) with the infected partner represented a significant risk for HIV infection, whereas general sexual activity (measured by the number of sexual partners and number of sexually transmitted diseases) was not associated with HIV infection. Although anal intercourse was found to be associated with HIV infection, this is not necessary for HIV transmission to occur. Vaginal intercourse has been inferred to contribute to HIV infection by this and other studies. Oral intercourse has been implicated in a small number of infections in men who have reported only receptive oral intercourse with other men.

RACE, CLASS, CULTURE AND AIDS: FACTORS THAT INFLUENCE THE INTERACTION BETWEEN CLIENT AND COUNSELOR

SOCIAL AND POLITICAL FACTORS	BEHAVIORAL MANIFESTATIONS	RISK FOR AIDS
1) Economics	- excluded from medical and social services - lack of or inferior education - drug abuse - prostitution - incarceration	- low quality health care and poor health status - lack of knowledge about AIDS, health and prevention - most educational materials written for people with high reading levels - potential to unknowingly infect others - late representation and diagnosis - no opportunity for treatment - cannot afford expensive drugs, i.e. AZT
2) Racism	- alienation and distrust of government, health care and social service system because of historical and current discrimination - internalized oppression	- belief in genocide theories - mistrust of AIDS information from government and health officials - fears about control of reproduction - self-defeating, negativity, passivity
3) Homophobia	- reluctance to identify as gay or bisexual - community denies existence of homosexual activity - inadequate and inappropriate health and social services	- information targeted to gays and bisexuals not perceived as relevant - heterosexual activity as cover for homosexuality - community doesn't acknowledge need for education
4) Sexism	- strict adherence to traditional sex roles (double standard; men have multiple partners, don't use condoms) - machismo - coercive sexual relations	- women don't have power to negotiate in sexual relationships - women at home; therefore, not available for education - women's value as mothers; therefore, reluctant to defer childbirth
5) Role of Religion, Culture, and Individual Values	- value placed on children - lack of fluency in English - strict adherence to traditional sex roles - unwillingness to discuss sexuality or drug use	- religious prohibitions on birth control and abortion - reluctance to defer childbirth - miss prevention messages because they are mostly in English - denial because of reluctance to confront issues of sexuality and drug use

SOURCE: Counseling and Education for the Prevention of AIDS. Jacalyn Lee, Elizabeth Schneee, and Nicholas Freudenberg. 1988

SOME SELECTED RESOURCES FOR THE CROSS CULTURAL TRAINER

Prepared by Robert Kohls for George Renwick's Update of the State-of-the-Art Study in connection with SIETAR's 10th Anniversary Conference at George Mason University, Washington, D.C.May 1984

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DRUG ABUSE INFORMATION

Drug abusers currently constitute the risk group with the second highest number of victims of AIDS and HIV infection. This group is potentially the hardest group to reach with educational and risk reduction messages. there are many reasons for this, the foremost being the illegal subculture of drug use itself.

HIV counseling in drug treatment centers offer some unique opportunities to educate this population of people at risk for HIV infection and AIDS. The best way to educate drug abusers is in a treatment program where counseling can begin. Counselors in drug treatment centers usually have a long term relationship with their clients, as opposed to the one time counseling sessions common in STD clinics. In this situation they can follow up on the clients and involve family members in various ways.

Many drug abuser treatment facilities are debating whether to offer HIV antibody testing on site. The biggest advantage of offering testing on site is the convenience and reliability of patient compliance. A client is much more likely to agree to testing if it is done immediately than if they have to travel to another site to have the test done. There is also less chance of confidentiality being compromised if the client only has to deal with one facility. However, if testing is done on site, there should be enough resources to provide high quality pretest and posttest counseling and support services to clients who need further help. All staff members should be provided basic information about AIDS, HIV infection, and infection control procedures.

USING CONDOMS

1. Condoms do not provide 100% protection against pregnancy and sexually transmitted diseases such as AIDS. However, properly used, condoms can reduce the risks of becoming pregnant or infected.

2. Consistently using FDA approved latex condoms offers the best protection against disease. Condoms made of animal membranes (sometimes called "natural") may be more likely to allow germs to pass through.

3. Condoms with a lubricant containing nonoxynol-9 have an additional chemical barrier against disease. Use only water soluble lubricants. Do not use oil based lubricants or saliva. Oil based lubricants, such as cooking oil or petroleum jelly, can damage the condom.

4. Never use outdated condoms. Always check the expiration data on the package.

5. Always store condoms in a cool, dry place. Heat can damage a condom.

6. Never use a condom more than once.

7. The correct way to use a condom is to remove it from the package and roll it down onto the erect penis, leaving a space at the tip to catch the semen. Don't unroll the condom before putting it on.

8. Use a condom from start to finish. Don't wait until you're ready for intercourse to put the condom on. Withdraw the penis while it is still erect. If the penis goes soft while still inside a partner, the protection can be lost.

9. When removing a condom, make sure you don't spill any of the semen. Also make sure you don't allow any semen to come in contact with any cuts or sores.

10. Dispose of used condoms by flushing down a toilet or putting in a trash bag.

HOW TO USE A DENTAL DAM FOR SAFER ORAL SEX

A dental dam, sometimes called an oral dam, is a six-inch square piece of thin latex, sometimes flavored, that's available at dental and medical supply stores. It should be placed over the entire vulva during cunnilingus to prevent the possible transmission of the HIV virus from the vagina. However, the dental dam is more flexible and therefore more fun and less likely to tear.

A. Always rinse the dam first, to remove the powder talc, which can contain asbestos and should never enter the vagina or anus. Pat it dry with a low-lint towel, or let it air-dry ahead of time. If you use a substitute, remember that some plastic, like that used for some garbage bags, can contain toxic chemicals that can endanger your health.

B. Spread the dam over the entire vulva, covering both the vaginal opening and clitoris, holding two edges of the dam with your hands. Then, use your mouth and tongue to stimulate your partner. In oral-anal contact, use the dam to cover your partner's anus. Don't share the same dam, never reuse it, and always use separate dams if you are practicing both oral-vaginal and oral-anal sex, because anal organisms can be harmful to the vagina.

C. There are some steps you can take to free your hands during oral sex. First, take a trip to a lingerie store. With a little creativity and a sewing kit, you can easily transform some elastic and garter clips, or a pair of erotic panties, into a fun and effective dental-dam holder that can be worn over the vulva or the mouth. Any materials you use should be washable and have no sharp edges. Remember to use a new dam each time you have oral sex.

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Editorial Review

HIV Infection Among Intravenous Drug Users: Epidemiology and Risk Reduction

Don C. Des Jarlais and Samuel R. Friedman*

AIDS 1987, **1**:67-76

Keywords: AIDS, intravenous drug use, HIV, epidemiology.

Introduction

Intravenous (IV) drug users are a critical group in the AIDS epidemic in the United States and Europe. They are the second largest group to have developed AIDS. IV drug use is a risk factor in 6948 out of 27843 (25%) of the adult cases in the United States (CDC AIDS Surveillance, personal communication, 1986). Out of these cases IV drug use was the primary risk behavior in 4760 (17%) and in 2188 (8%) both male homosexual activity and IV drug use were risk behaviors. In Europe, in 499 out of 3251 (15%) of the adult cases, IV drug use was a risk behavior, in 418 (13%) IV drug use was the primary risk behavior, and in 81 (2%) both IV drug use and male homosexuality were risk behaviors (Brunet, personal communication, 1986). The percentage of American AIDS cases with IV drug use as the risk behavior has been quite stable over the last several years. The percentage of European cases attributable to IV drug use has been increasing rapidly: in September 1984, IV drug use was the primary risk behavior in only 2% of adult European cases; in September 1985 this had increased to 6%, and in September 1986 to 13%.

Once HIV becomes established among IV drug users in a local area, drug users become a primary source for heterosexual and *in utero* transmission. In New York City, IV drug users are the apparent source of the virus in 87% of the cases in which heterosexual activity is believed to be the mode of transmission, and in 80% of the cases of maternally transmitted AIDS (data from the New York City Department of Health, up to October 15 1986). Control of the AIDS epidemic in the United States and Europe will thus require control of HIV infection among intravenous drug users.

In this paper, we will review current research on AIDS and HIV seroprevalence among IV drug users in the United States and Europe, on behaviors associated with HIV exposure among IV drug users, and on current and potential risk reduction among IV drug users. Research on AIDS among IV drug users is still at a relatively early stage. Many of the studies reviewed here have been presented at scientific conferences but have not yet been published in final form. Nevertheless, areas of consistency are emerging across studies that can serve to guide future research. Given the urgency of the need to prevent additional HIV infection, they will also have to guide public health policy decisions.

Epidemiology of AIDS and HIV infection among IV drug users

Probably the best single piece of information for predicting whether an individual IV drug user is likely to have been exposed to HIV is geographic location. Tables 1 and 2 show seroprevalence rates among IV drug users studied in different parts of the United States and Western Europe. While differences in recruitment of the samples undoubtedly account for some of the differences in seroprevalence rates, there is still very great geographic variation, from 2% in New Orleans (Ginzburg, personal communication, 1986) to approximately 70% in Milan [2].

In the United States, the New York City area clearly has the highest seroprevalence rate. This area also has had the greatest number of cases of AIDS among IV drug users – throughout the epidemic over 75% of the IV drug use AIDS cases in the USA have been from the states of New York and New Jersey (CDC AIDS Surveillance, personal communication: drug users with male homosexuality as a risk factor not included).

Studies of HIV seroprevalence among IV drug users in Europe also show a wide range. There is a general north-south difference, with higher rates among IV drug

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Table 1. HIV seroprevalence among intravenous drug users in the United States.

Location	Date of sera collection	Reference
High seroprevalence 50% or higher		
Manhatten, NYC	1984	[7]
Northern New Jersey	1984	[8]
Moderate seroprevalence: 20–49%		
Bronx, New York	1985	[11]
Boston	1985	(Hutchinson, Craven, personal communication, 1987)
Low seroprevalence: 5–19%		
Chicago	1984	[21]
San Francisco	1984	[21]
	1985	[9]
Washington, DC	1985	(Ginzburg, personal communication, 1986)
Very low seroprevalence: less than 5%, but greater than 0%		
New Orleans	1985	(Ginzburg, personal communication, 1986)
Southern New Jersey	1984	[8]

Table 2. HIV seroprevalence among intravenous drug users in Western Europe.

Location	Date of sera collection	Reference
High seroprevalence: 50% or greater		
Southern Italy	1985	[41]
	1985	[2]
Spain	1985	[42]
	1985	[43]
Edinburgh, Scotland	1985	[6]
Moderate seroprevalence: 20–49%		
Berlin, FDR	1985	[44]
	1985	[2]
Zurich, Switzerland	1985	[45]
Amsterdam, Holland	1985	[10]
Dublin, Ireland	1985	[46]
Low seroprevalence: 5–19%		
Copenhagen, Denmark	1985	[5]
Stockholm, Sweden	1985	(Helgessen, personal communication, 1986)
Very low seroprevalence: less than 5%, but greater than 0%		
Yugoslavia	1985	(Data from Yugoslavia, Department of health)
Glasgow, Scotland	1985	[47]

users in southern Europe. This gradient also applies within some countries, e.g. France (Brunet, personal communication, 1986) although not in the United Kingdom where Edinburgh has the highest seroprevalence rates.

In Europe, Italy and Spain have high seroprevalence rates and the greatest numbers of AIDS cases among IV drug users, 187 cases and 93 cases, respectively. Over 50% of the AIDS cases in each of these two countries have been among IV drug users. France with 58 and the Federal Republic of Germany with 41 are the other two European countries with high numbers of IV drug user AIDS cases, and Switzerland, with 18, must be considered to have a high number relative to its population (Brunet, personal communication: IV drug users with male homosexual risk behavior not included).

The explanation for the great differences in HIV seroprevalence rates within the USA and Europe is a major problem in the epidemiology of HIV among IV drug users. Part of the explanation clearly is the date of first introduction of the virus into the local group of IV drug users. Historically collected sera from IV drug users show the first seropositive sample from New York City was collected in 1978 [3], from northern Italy in 1979 [2], from the Federal Republic of Germany in 1982 [4], and from Denmark in 1984 [5].

The studies of historically collected sera also show that, once the virus has been introduced into a local community of IV drug users, very rapid spread is possible. In southern Manhattan, seroprevalence rose to over 40% by 2 years after the first seropositive sample [3]. In Edinburgh, seroprevalence rose to approximately 50% within 2 years of the first seropositive sample [6], and in Milan to approximately 50% within 4 years after the first seropositive sample [2].

Behavioral factors associated with seropositivity

There have been only a limited number of studies that examine different behavioral factors associated with sharing of injection equipment and HIV seropositivity [7–11]. Despite the limited number of studies, the findings permit some conclusions about behavioral factors associated with sharing equipment and HIV seropositivity.

The frequency of drug injection was associated with seropositivity in the studies from the New York area [7,8,11]. This finding is consistent with the pre-AIDS observations that sharing drug injection equipment was normal behavior among IV drug users. The more one injected, the more frequently one would use equipment that another person had already used, and the more likely one was to become infected with HIV.

The second behavioral factor that has been associated with HIV exposure in different studies has been the use of 'shooting galleries' as a place to inject drug [7,8] (Chaisson, personal communication). Shooting galleries are places where IV drug users can rent injection equipment, which is returned to the owner and then rented to the next customer. They provide for sharing drug injection equipment with large numbers of other drug users. Use of shooting galleries may be considered the functional equivalent of having large numbers of homosexual partners in the early stages of the AIDS epidemic among gay men.

In addition to frequency of injection and the use of shooting galleries as factors associated with HIV exposure among IV drug users, there are two demographic variables that should be mentioned. These variables are not consistently associated with HIV exposure across studies, but have sufficiently important policy implications that they deserve to be mentioned. Females have had higher rates of HIV exposure in studies conducted in Manhattan [7] and West Berlin [4]. In addition, prostitutes were found to have higher seroprevalence rates in Manhattan [12] and the Bronx [11]. HIV exposure among prostitutes does not appear to be the result of transmission from customers. In a national study of HIV exposure among prostitutes, Darrow and colleagues found that the use of shooting galleries and unprotected sexual intercourse with IV drug using boyfriends was associated with HIV exposure, but not the total number of sexual contacts [13]. When multivariate analyses were done in these studies, male–female differences and differences between IV drug using female prostitutes and IV drug using females who did not report prostitution generally lost statistical significance. Nevertheless, it is clear that IV drug using women, almost all of whom are of childbearing age, will present a growing problem for *in utero* transmission. To the extent that female-to-male transmission does occur in North America and Western Europe (the efficiency of this transmission is currently a subject of intense debate) IV drug using prostitutes are an important potential source of heterosexual transmission.

Studies of ethnic differences in HIV exposure among IV drug users have found that minority group members have higher rates than whites in Manhattan [7], the Bronx [11], and San Francisco [9]. Multivariate analyses (controlling on drug injection frequency and use of shooting galleries) usually caused these differences to lose statistical significance, but it is clear that in the USA, HIV has spread more extensively among non-white IV drug users. This will present complicated public health problems to limit further spread among minority IV drug users and the associated heterosexual and *in utero* transmission.

In Europe, there are not yet sufficient data to address the question of seroprevalence among ethnic groups. Potentially higher rates of IV drug use within immigrant communities and the ease with which IV drug users can cross national boundaries, however, indicate potential difficulties in conducting AIDS prevention efforts for IV drug users.

There is currently very little evidence for a simple relationship between HIV seroprevalence among IV drug users and the legal restrictions on the sale of sterile needles and syringes. The most convincing evidence comes from Edinburgh, where the legal supply of sterile equipment was restricted (through police persuading pharmacists not to sell needles and syringes to drug users) at about the time that HIV was introduced into the community. This was followed by very rapid spread of the virus among IV drug users, reaching approximately 50% within 2 years after the virus was introduced into the area [6].

Italy provides the strongest counterexample. Sterile needles and syringes are legally available without prescription; indeed they are often sold in supermarkets. This legal availability has not prevented the rapid spread of HIV among IV drug users in the northern part of the country.

In the United States, prescriptions are required for the sale of needles and syringes in only 12 states [14]. Most of the states with high concentrations of IV drug users do require prescriptions, e.g. New York, New Jersey, California and Illinois, but not all do, e.g. Missouri and Louisiana. New Jersey has areas of both high and very low seroprevalence.

In Europe, only Sweden currently requires prescriptions. France and Switzerland only recently removed prescription requirements as AIDS prevention measures. Again there is no simple relationship to AIDS among IV drug users, as Switzerland is considered to have a relatively 'high' rate of HIV infection among IV drug users, France an 'average rate' and Sweden a 'low' rate [15].

'Needle exchange' programs, in which IV drug users may return used needles and syringes in exchange for sterile ones, have been in operation in Holland for several years and have recently been established in he United Kingdom, and at the time of writing were being considered in France and New York. There are, however, no data yet indicating that these programs have been successful in reducing the spread of HIV.

This current lack of a simple relationship between the legal restrictions on the purchase and possession of needles and syringes should not be considered surprising. The data in Tables 1 and 2 largely represent spread of HIV before any awareness among IV drug users of the dangers of AIDS. As noted above, the sharing of drug injection equipment was a normal part of the IV drug use subculture before any awareness of AIDS. Thus, the extent to which an increased availability of sterile equipment when coupled with an awareness of AIDS will reduce HIV infection among IV drug users must be considered an open question at this point.

Despite the wide variation in seroprevalence rates in the USA and Western Europe, the risk factor studies conducted to date show a limited number of behavioral factors that are typically associated with HIV exposure. Frequency of drug injection and use of shooting galleries (sharing equipment with large numbers of other IV drug users) appear to be frequently associated with HIV exposure, suggesting that effective prevention programs need to focus on reducing these two factors. Belonging to an ethnic minority group and engaging in prostitution may be additional risk factors, indicating the need for prevention programs that include special components for prostitutes and incorporate ethnic differences. Before considering prevention strategies, however, it is necessary to consider the question of whether IV drug users are capable of changing AIDS related risk behavior.

Current AIDS risk reduction efforts among IV drug users

The impression that drug users are 'self-destructive' has led many public officials to conclude that IV drug users will not change their behavior to avoid AIDS. (In addition to this belief, there are real social organizational and physiological impediments to AIDS risk reduction among IV drug users [1,16].) While there have been only a limited number of studies of behavior change among IV drug users in response to the threat of AIDS, all of them have shown substantial numbers of IV drug users adopting some form of AIDS risk reduction.

In 1984, all of a sample of 59 methadone maintenance patients whom we interviewed had heard of AIDS; 55 (93%) of them knew that IV drug use is a mode of transmission of the disease. The majority (61%) of these subjects also were able to name at least one AIDS symptom correctly, with the most frequently named symptoms being weight loss (36%) and fatigue (31%). Fifty-nine per cent of the subjects reported some form of risk reduction to avoid AIDS; 54% reported changes in injection-related behavior. The most common changes were increased use of clean needles and/or the cleaning of needles, reported by 31%, and reducing needle sharing, reported by 29%. Fourteen per cent reported reducing their level of IV drug injection. (These subjects were primarily injecting cocaine, for which methadone has no chemotherapeutic effect.) Fifty-one per cent of the group also reported that friends had changed their behaviors to avoid AIDS [16].

In the summer of 1985, Selwyn *et al.* [17] studied IV drug users in jail (n = 115) and methadone maintenance clients (n = 146) with findings remarkably similar to those from our methadone maintenance subjects. Ninety-seven per cent of the two Selwyn samples knew that sharing needles could transmit AIDS. Over 60% of these subjects reported risk reduction. Reducing (or eliminating) needle sharing was the most common form of risk reduction in both samples.

Support for the validity of these reports from individual IV drug users can be seen in studies of the marketing of illicit needles and syringes in New York City. These studies show evidence of a large scale change in the demand for sterile needles and syringes for injecting drugs. In the spring of 1985, we conducted interviews with people selling needles and syringes in the drug dealing areas of New York City [18]. Eighteen out of 22 needle sellers reported that sales had increased over the previous year, four specifically mentioned AIDS as the reason for the increased demand.

The increased demand for sterile needles and syringes is sufficiently strong to support a market in 'counterfeit' sterile needles. The people selling needles and syringes were also asked if they had ever sold used needles as new; 10 out of 21 (48%) reported that they occasionally repackaged used equipment and then sold it as new. This 'counterfeit' sterile needle phenomenon had not been observed in the city before awareness of AIDS, and indicates both the strength of the increased demand for sterile equipment and the hazards of relying upon an illicit market for sterile drug injection equipment.

In the fall of 1985, we observed additional AIDS related changes in the marketing of needles and syringes for illicit drug injection. Some needle sellers were including an extra needle with the sale of a 'set' of a needle and syringe. If the first needle gets clogged, it can immediately be replaced with the extra needle. This reduces the chances that a clogged needle would lead an IV drug user to rent or borrow a used needle. Finally, drug dealers have been including a new set of works as a marketing device with $25 and $50 bags of heroin [19].

These studies of changes in the marketing of illicit sterile needles in New York not only suggest that the self-reported changes in needle use by drug users are valid; they also suggest that AIDS risk reduction is occurring among IV drug users who are not in treatment. (The great majority of IV drug users are not in treatment at any point in time, and IV drug users in treatment inject drugs at levels greatly reduced from those out of treatment. The changes in the marketing of illicit needles and syringes should therefore be seen as primarily resulting from an increased demand for sterile equipment from IV drug users not in treatment.)

Both concern about AIDS and risk reduction to avoid exposure to the virus have developed among IV drug users in the New York metropolitan area, where HIV seroprevalence is approximately 50%, and where there are almost 3000 IV drug users who have already developed CDC (Centers for Disease Control) surveillance definition AIDS. An important question for control of the epidemic among IV drug users in other areas is whether risk reduction will occur before extensive spread of the virus and/or development of large numbers of cases of AIDS among IV drug users. Preliminary data from Amsterdam and San Francisco are encouraging on this point.

In Amsterdam, the HIV seroprevalence rate among IV drug users is estimated to be between 25% and 35%, and, to date, there have been only a few cases among IV drug users. Preliminary studies nevertheless indicate that significant risk reduction is occurring. In a retrospective study of self-reported behavior change over a 6-month period among 164 IV drug users, Coutinho and his colleagues found both a decline in the percentage who inject more than once per day, and an increase in the percentage using the 'needle exchange' to obtain sterile needles and syringes [20].

HIV seroprevalence among IV drug users in San Francisco is estimated to be between approximately 10 and 20% [9,16]. Biernacki and Feldman [22] have been conducting ethnographic research on IV drug users not in treatment in that city. They report that AIDS is already a topic of 'grave concern' among IV drug users there, and that the drug users want to learn how to protect themselves against exposure, including how to sterilize needles and syringes. Before any widespread prevention campaigns aimed at IV drug users, a 'substantial minority' had already reduced the numbers of people with whom they would share drug injection equipment.

Prevention strategies

The AIDS risk reduction discussed above has primarily been the result of information carried by the mass media and by the oral communication networks within the IV drug use subculture, rather than the result of any public prevention efforts. Specifically targeted prevention efforts should be able to produce greater levels of AIDS risk reduction among IV drug users than have been observed to date.

In discussing AIDS prevention among IV drug users, it is important to avoid stereotyping all IV drug users as the same. There are important differences among current and potential IV drug users that will require different strategies for successful AIDS prevention. The epidemiological studies suggesting that ethnic minorities and prostitutes may have higher HIV seroprevalence rates indicate a need for prevention programs that consider the special circumstances of these groups.

In addition to these considerations, specific prevention programs should include the likelihood of future IV drug use as a major consideration. Conceptualizing prevention programs in terms of the likelihood of future IV drug use provides three target groups for AIDS/HIV prevention:

(1) those who have not begun IV drug use;
(2) those who are willing to enter treatment to eliminate IV drug use, and
(3) those who are unwilling to enter treatment and/or those for whom present forms of treatment are unlikely to be successful.

People who have not begun IV drug use

The ideal point for prevention of AIDS among IV drug users would be to prevent initiation into IV drug use. This would not only prevent needle sharing transmission of HIV, it would also prevent the many other health and social problems associated with IV drug use.

Educational programs about the dangers of AIDS and IV drug use are already being developed for use in secondary schools. While such programs certainly should be supported, there are likely to be limits on their effectiveness. First, drug prevention programs based on fear arousal have not been very successful in the past [23], particularly if the fear is associated with a low probability event or there is a long time period between the 'risky' drug use and the adverse consequences. Second, many people who eventually become IV drug users drop out of school well before they make decisions about injecting drugs.

Prevention programs targeted at reducing initiation into IV drug use may have to operate outside school settings. Rather than merely disseminating information about the dangers of AIDS, they may also have to focus on teaching skills needed to resist social pressures to begin injecting drugs (similar to cigarette smoking prevention programs that focus on teaching skills to resist initiation into cigarette smoking). Such programs undoubtedly are more difficult to operate than the in-school programs, but they will be necessary to reach those at highest risk for beginning drug injection. Programs working with people at high risk of beginning injecting also pose some difficult policy/strategic questions such as: should they focus only on preventing drug injection (the AIDS danger), or should they be broader and focus on any use of such drugs as cocaine and heroin, or broader still and try to focus on any illicit drug use? Preventing non-injected drug abuse is a valid public health goal in itself, but may dilute efforts to reduce the AIDS-specific problem of initiation into drug injection.

Reducing initiation into IV drug use may be the most effective long-term strategy for reducing the spread of HIV through sharing drug injection equipment. Given the likelihood that IV drug users will be active heterosexuals and have children, it may also be a necessary strategy for reducing heterosexual and *in utero* transmission. Yet we know very little about how AIDS has (or has not) affected initiation into IV drug use. This is clearly a critical area for research on long-term prevention.

Preventing AIDS through reducing initiation into IV drug use certainly will be required as part of a long-term effort to control AIDS. The number of current IV drug users at risk for HIV infection, however, is sufficiently large to require extensive prevention programs.

Current IV drug users who would enter treatment

Entering treatment has been associated with large reductions in the rate of IV drug use, particularly for heroin injection [24]. Fear of AIDS, among other reasons, will undoubtedly lead significant numbers of IV drug users to seek treatment for their drug use. Current data from New Jersey, where people entering treatment are specifically asked their reasons for entering, show that approximately half of the IV drug users now entering give fear of AIDS as one of their reasons for entering treatment [25].

For the USA as a whole and in some parts of Europe, however, the availability of treatment was significantly less than the demand even before the AIDS epidemic. Expanding the treatment system could significantly reduce IV drug injection and transmission of HIV among IV drug users. Users who had not been exposed would greatly reduce their chances of being exposed, and users who had already been exposed would greatly reduce their chances of exposing others. The economics of treating AIDS (approximately $100 000–150 000 per case in New York) versus providing drug abuse treatment (approximately $3000 per patient year) also argue for expansion of the treatment network.

Unfortunately, there are real factors other than finances that currently limit the availability of drug abuse treatment. Drug abuse treatment has general approval within Western society, but is particularly subject to local neighbourhood opposition. In addition, methadone maintenance treatment, which tends to be the most acceptable treatment modality to large numbers of IV drug users, also tends to have the least degree of acceptance among the general public and by the criminal justice system.

Finally, if there is to be significant reduction of HIV transmission through increased treatment, the program expansion will have to be on a large scale. Based on our New York experience, we would estimate that there are approximately six IV drug users not in treatment for every one currently in treatment. Thus, to control HIV transmission among IV drug users through additional treatment would require a massive expansion of the treatment system, not just an incremental expansion.

IV drug users who do not wish to enter treatment

There are many current IV drug users who wish to reduce their chances of exposure to HIV but do not wish to enter treatment. In addition, treatment is not likely to be immediately successful in eliminating IV drug use for many who do enter. The studies in New York and elsewhere indicate that these IV drug users who are very likely to continue injecting drugs will try to modify their needle use behavior to avoid AIDS.

One strategy for reducing the spread of HIV among people who are likely to continue injecting drugs is to increase the legal availability of sterile needles and syringes. This has been the subject of much public discussion in New York, New Jersey and California, though none of these states has adopted any program to provide sterile drug injection equipment to IV drug users. Concern about AIDS among IV drug users has also led to public discussion of increasing legal availability of sterile injection equipment in France and Sweden, and to removal of prescription requirements in Switzerland, and establishment of needle exchanges in the United Kingdom. Increasing the legal availability of hypodermic needles has received support among public health officials. It has generally been opposed by law enforcement officials, who predict that it either would not be effective because IV drug users would not change their behavior, or that it would be 'too' effective and increase the number of IV drug users by removing the threat of AIDS.

The actual effects of increasing the legal availability of sterile needles and syringes are unknown. Almost no data have been systematically collected about the relationships between the legal availability of sterile equipment and levels of IV drug use prior to the AIDS epidemic. Even if such prior information were available, it is questionable whether it could be generalized to the AIDS situation, since the threat of AIDS may be radically changing many aspects of IV drug use. The preliminary findings from Amsterdam indicate that IV drug users will return equipment (so that disposal of the used equipment is not a major problem), that there has been no decrease in demand for either methadone or drug-free treatment, and that there has been no increase in IV drug use [26]. There is as yet no evidence that the needle exchange program has reduced spread of HIV, but such effectiveness may depend upon the increasing concern about AIDS and use of the needle exchange noted above [20].

In light of the current lack of information regarding the legal distribution of sterile equipment to IV drug users as a method of preventing AIDS, the National Academy of Sciences–Institute of Medicine has specifically called for research in the United States on this topic [27].

A related method of attempting to reduce HIV transmission among IV drug users who are very likely to continue injecting illicit drugs is education about not sharing needles and on how to 'clean' needles properly in order to kill HIV. The United States Public Health Service has called for research on increasing the use of sterile equipment by IV drug users not in treatment [28]. Printed information is being distributed in several parts of the USA, sometimes supplemented with face-to-face instruction on how to sterilize needles. (The messages emphasize that stopping drug injection is the only certain method for avoiding HIV infection from contaminated works.) Such programs are currently operational in New York City, New Jersey, San Francisco, Baltimore, Chicago and Washington, DC.

Interactions among prevention strategies

It is possible to see 'inconsistencies' among these strategies for preventing AIDS among groups that differ according to the likelihood of future IV drug injection. Providing for any form of 'safer injection' may be viewed as encouraging non-injectors to start injecting drugs, and as discouraging current IV drug users from entering treatment and stopping IV drug use. Because these perceived inconsistencies may lead to failure to develop any AIDS prevention programs among IV drug users, several brief comments are appropriate.

First, the abuse of psychoactive substances is associated with a variety of complex social and health problems. A mixture of educational, therapeutic and law enforcement methods is utilized to try to minimize these problems. This mixture of strategies has been adopted because no single approach has been effective by itself. Because a mixture of strategies is used, it is relatively easy to find numerous 'logical inconsistencies' between the different methods. Conflict between therapeutic and law enforcement approaches to reducing addiction certainly has existed throughout the history of drug abuse in the United States [29–31]. Adaptation to this conflict has usually been through the use of separate agencies with separate missions and the setting of priorities when working with individuals, with a current consensus that neither approach is likely to be sufficiently effective by itself. AIDS is a new and potentially catastrophic problem associated with drug abuse. Use of a single strategy to try controlling AIDS among IV drug users is no more likely to be successful than use of a single strategy is in controlling the overall problem of drug abuse in society.

The second comment concerns our very limited ability to predict just what does 'encourage drug abuse' and what does prevent HIV infection among IV drug users. The mass media coverage of AIDS among IV drug users in New York City appears to have led to both an increase in the use of sterile equipment and, to a smaller extent, a decrease in the frequency of injection. Data from Amsterdam indicate that the needle exchange program has not led to any increase in drug injection nor to a reduction in the demand for either methadone or drug-free treatment [26], but has not yet led to an observable reduction in the spread of HIV [10].

Preliminary data from New York (Kleinman, personal communication, 1986), New Jersey [25] and San Francisco (Newmeyer, personal communication, 1986) indicate that educating IV drug users in how to sterilize illicit drug injection equipment leads many of them to want to enter treatment for their drug abuse. Consistency on the need to prevent HIV infection appears to be overriding any potential inconsistency between sterilizing needles versus entering treatment to stop IV drug use. Efforts to prevent AIDS through increasing the use of sterile equipment and through providing drug abuse treatment to stop IV drug use may be mutually reinforcing strategies rather than contradictory ones.

Given the heterogeneity among current (and potential) IV drug users, it is highly unlikely that any single approach to the prevention of HIV infection will be sufficient for all IV drug users. Determining the optimal mixture of strategies will require careful evaluation of different prevention programs integrated with monitoring of the spread of the virus. The mixture of strategies to maximize the prevention of AIDS can be expected to vary in different communities and across time in a single community.

HIV antibody testing and AIDS prevention

HIV antibody testing has been advocated as a potentially powerful technique for reducing the transmission of HIV [28]. There are only limited data on the effects of HIV testing on AIDS-related behavior in IV drug users. Two papers were presented at the Paris conference showing dramatic short-term reductions in needle use transmission behavior following feedback of test results [32,33]. Both of these studies were conducted within treatment settings, the decision to provide counselling was supported by the treatment staff, there was extensive pre-test counselling, the testing was totally voluntary, and extensive precautions were taken to assure confidentiality of the test results. When HIV antibody testing is done without these extensive supports, there appears to be no net positive effect on AIDS risk behavior, and a potential for harm to the individuals participating [25]. Even with the intensive supports, antibody test feedback is likely to produce increases in anxiety and depression [32]. In terms of reducing AIDS risk behavior, it is probably a mistake to think of 'antibody testing' as a prevention technique. Instead, one should think of intensive counselling with testing as an adjunct to the counselling.

Self-organization and AIDS prevention

Although there are no data on the competitive efficacy of the 'causes' of AIDS risk reduction among gay men, organizations of gay men have been very active in promoting risk reduction. Despite the inherent difficulties in creating formal organizations of IV drug users, there is the potential that self-help organizations of current and/or former IV drug users might be able to create new social norms that would discourage the sharing of drug injection equipment.

The most developed form of drug user formal organization is undoubtedly the Dutch 'junkiebonden' (drug users' unions, or JBs). The JBs formed in the early 1980s as an attempt by drug users to influence government drug laws and the way in which Dutch drug treatment programs were run. They initiated a needle exchange program in response to the danger of hepatitis. More recently, they have been an essential vehicle for distributing syringes and needles as part of the official Dutch anti-AIDS needle exchange programs, and they have written their own pamphlets and conducted other educational efforts. They have not yet been able to plan and implement a broad plan for subcultural change to reduce HIV transmission, but they have established a degree of self-awareness and identity among Dutch IV drug users that will be a valuable resource for collective efforts at mutual protection (for more detail about the JBs, including analyses of their strengths and weaknesses, see [34,35]).

In New York, former IV drug users, methadone patients, health professionals, and current drug users have set up an explicitly AIDS-oriented organization to educate IV drug users about AIDS, give support to the sick, give drug users a voice in AIDS policy, and do whatever they can to reduce HIV transmission to and by IV drug users. Their activities have included going into drug selling areas to teach users about AIDS; visiting shooting galleries and negotiated with their owners to have sterile works on hand as well as bleach, clean cotton, clean plastic cups, garbage bags, and other equipment; and conducting training sessions for drug program staff and clients.

Another, more limited, form of drug user organization has taken place in some drug treatment programs. Here, staff members have initiated discussion groups to work through what the existence of HIV means for the lives of participants and to help individuals figure out how to cope with their changed environment. In some cases, the drug users in these groups have become interested in spreading the facts about AIDS, and their ideas about how drug users can protect themselves, to other program clients and to drug users on the streets. These self-help groups seem to offer an opportunity both for effective outreach and also for the development of support among their active participants for self-protective behavior [36].

Heterosexual and *in utero* transmission of HIV

While this paper is restricted to reviewing current data on the sharing of drug injection equipment and the transmission of HIV, a brief discussion of heterosexual and *in utero* transmission is also needed. As noted in the introduction, once HIV becomes established within a local group of IV drug users, they can become the predominant source for both heterosexual and *in utero* transmission in the area.

Both our 1984 data on risk reduction among methadone patients [16] and the Selwyn *et al.'s* 1985 data on methadone patients and IV drug users in prison [17] showed risk reduction for heterosexual transmission, although this was reported by smaller percentages than were reporting IV drug use risk reduction. The number of public health messages for heterosexuals to use condoms has been increasing rapidly in both the United States and Europe, and there are some drug abuse treatment programs in the USA and Europe that are now distributing condoms as a regular activity. Voluntary antibody testing may be particularly helpful in reducing heterosexual and *in utero* transmission from IV drug users as it would at least identify seronegatives who would have little worry of transmitting the virus. The situation is quite difficult for seropositive IV drug users. The danger of heterosexual transmission may lead sexual partners to break off relationships at a time when the newly informed seropositive needs psychological and social support [32]. To decide permanently against having children would have great psychological cost for many IV drug users.

Consideration of the difficulties in preventing heterosexual and *in utero* transmission reinforces the need to prevent HIV transmission through sharing of drug injection equipment.

Natural history of HIV infection in IV drug users

There has been very little study of the outcomes of HIV infection in IV drug users. One study found that two out of eight seropositive IV drug users developed AIDS within 3 years [37], and we found an annual incidence of 4% for development of AIDS in a 9-month follow-up [38]. These rates are similar to the rates for the development of AIDS among seropositive gay men in New York City. There are, however, two aspects of the natural history of HIV infection that could increase motivation for behavior change/risk reduction among IV drug users.

First, in our cohort study, high levels of continued drug injection were associated with increased rates of HIV-related immunosuppression (T4 cell loss) in seropositive IV drug users. If AIDS prevention efforts include a warning that continued injection may increase immunosuppression, this may lead seropositive IV drug users to reduce their levels of drug injection and therefore the likelihood that they would transmit HIV to others. (Provision of drug abuse treatment for seropositives may be needed for this to have an effect on a public health scale level.)

The second aspect of the natural history of HIV infection among IV drug users is the possibility that AIDS deaths greatly underestimate the number of fatal outcomes of HIV infection in the group. Since HIV was first introduced into the IV drug use group in New York City, there has been a dramatic increase in the annual numbers of recorded deaths among IV drug users from approximately 250 in 1978, to approximately 2000 in 1986 [18,33]. Deaths from AIDS account for only half of this increase, with non-pneumocystis pneumonia and endocarditis being among the rapidly growing other causes of death among IV drug users in New York City. There has also been an epidemic increase in tuberculosis among IV drug users over the same time period [40]. Research on possible relationships of HIV infection to the 'non-AIDS' excess deaths and to the increase in tuberculosis is currently being conducted. If IV drug users perceive HIV infection as likely to lead to a variety of very serious health problems in addition to the possibility of developing AIDS, their motivation to reduce AIDS-risk behavior could be strengthened.

Summary

Research on the epidemiology of HIV infection among IV drug users is still at a relatively early stage. Multi-location studies that would permit better geographic comparisons are greatly needed. Multi-method studies within single geographic areas are also needed to assess possible biases with respect to sample recruitment and data collection procedures. The continuation of the epidemic provides a changing historical context that complicates any comparisons. Despite these problems, there are some consistencies that can be seen across studies.

Studies of HIV seroprevalence among IV drug users show wide variation among cities in the United States and Europe. The time that the virus was introduced into the IV drug using group within the city is one factor in explaining these differences; other cross-city factors have yet to be identified. Once HIV has been introduced into the IV drug use group within a particular geographic area, there is the possibility of rapid spread up to seroprevalence levels of 50% or greater. Thus, a currently low seroprevalence rate should not be seen as a stable situation.

Frequency of injection and sharing of equipment with multiple other drug users (particularly at shooting galleries) have been frequently associated with HIV exposure. Being female, ethnicity (in the USA) and engaging in prostitution also may be associated with increased risk for HIV exposure, suggesting that prevention programs should include special consideration of sex and ethnic differences.

Studies of AIDS risk reduction show that substantial proportions of IV drug users are changing their behavior to avoid exposure to HIV. This risk reduction is probably more advanced in New York, with its high seroprevalence and incidence of cases, but is also occurring in cities with lower seroprevalence and limited numbers of cases. The primary forms of risk reduction are increasing the use of sterile equipment, reducing the number of needle sharing partners, and reducing the frequency of injection. These behavior changes are very similar to the frequently identified behavioral risk factors associated with HIV exposure, suggesting that they should be effective in at least slowing the spread of HIV among IV drug users. No linkage of risk reduction to decreases in seroconversion has yet been shown, however, and greater risk reduction is clearly required.

A variety of prevention strategies will probably be needed to reduce the spread of HIV among IV drug users. Prevention of initiation into drug injection is an undeniable long-term goal for the control of HIV infection, but there is very little research being conducted in this area. Increasing the availability of drug abuse treatment and increasing the use of sterile equipment among people who continue to inject have been two commonly suggested means for reducing the spread of the virus among current IV drug users. While it is possible to see contradiction between these two strategies, the very limited available data from places where both have been put into effect indicate that the two strategies probably reinforce each other rather than detract from each other. While there is considerable evidence that AIDS prevention is quite feasible among IV drug users, the present state of knowledge on how best to achieve this is limited. Much more research and demonstration activity is needed.

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ORIGINAL CONTRIBUTION

AIDS: Relationship to Alcohol and Other Drugs

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Abstract—*Most people who are exposed to AIDS do not get the syndrome. It seems clear that there must be cofactors. Most people with AIDS have a history of alcohol or other drug use, and many of the drugs used have been shown to suppress the immune system. The correlation between drug use and development of AIDS in several populations is striking, and it is suggested that definitive research into this possible cofactor be urgently initiated. The elimination of cofactors may present an immediate way to control this epidemic. Suggestions are made as to how and why alcohol and drug treatment professionals should become a part of this effort.*

Keywords—AIDS, alcohol, drugs, relationship, cofactors

INTRODUCTION

Two OF THE MOST interesting questions being asked about Acquired Immunodeficiency Syndrome (AIDS) will be discussed in this paper. The first is why do so many people not become immunodeficient or contract the complicating diseases when exposed to the widely believed causal agent, a retrovirus most commonly called HTLV-III and recently renamed Human Immunodeficiency Virus (HIV). The second is what is there about the "risk" groups that make them susceptible. Why some exposed people do contract it and others do not—that is the question. The fact that direct exposure alone does not usually cause AIDS is now known, based on the hundreds of direct exposure to body fluids of all kinds by health workers, with perhaps only two having developed evidence of exposure (HIV+) and none having developed AIDS (Centers for Disease Control, 1986). In addition, seven studies have been performed involving over 350 family members of people with AIDS with close nonsexual contact, and only a single family member (a mother who used no precautions caring for a very sick infant) has developed serologic or virologic evidence of HIV transmission, again demonstrating how difficult it is to get this infection (Centers for Disease Control, 1986).

Whereas very long-term effects are not predictable at this time, it is known that at least over a six-year period between 60% and 90% of homosexual men infected with HIV did not get AIDS (Jaffee et al., 1985). Recent documentation of the presence of the HIV antibody in 25% to 41% of nonrisk group patients with acute malaria but without AIDS further suggests that the exposure to HIV alone is not sufficient for the development of AIDS (Volsky et al., 1986). However, there are still questions as to why the male homosexual population in the U.S. is especially susceptible and what there is about other populations (such as heterosexual blacks in Belle Glade, Florida) that relates to their high incidence.

BACKGROUND

The presence of something in addition to the HIV virus exposure seems to be required to acquire the virus and become ill from it. One or more cofactors must exist. A variety of such cofactors have been proposed (Seligmann et al., 1984), including repeated exposure to the HIV virus, nutrition, and other coincident infections. In spite of this, very little investigation has been done of some of the more obvious cofactors, such as the use of ethyl alcohol and other drugs by people who get AIDS.

M.E. Whiteside and C.L. MacLeod (letter to James Howell, M.D., State of Florida Health Officer, 1986),

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among others, have repeatedly pointed out that there must be environmental factors that either predispose to the acquisition of AIDS or are cofactors at the time of exposure to the causative virus. What needs more investigation is whether the "internal cellular environment" might not require alteration in order to allow infection and whether that alteration may not be exactly what happens in any of the so-called "high risk" populations that develop AIDS. Of even greater possible impact is the suggestion that removal of such potential precursors or determinants (e.g., alcohol and other drugs) may allow for recovery from and/or avoidance of AIDS in individuals who have not yet progressed to the full-blown syndrome.

Drugs, including alcohol, have been used by at least 80% of homosexual men with AIDS (C.A. Caceres, personal letter, 1986; Cohen, 1985). In a review of data compiled by the Centers for Disease Control (CDC), Guinan et al. (1984) found that the adult heterosexual AIDS patients who had been tabulated as having "no identified risk" were reported as users of marijuana. Of 50 homosexual men, 96% had used nitrites, 80% had used marijuana, 66% had used nasal cocaine, and 50% had used ethyl chloride (Guinan et al., 1984). No questions were asked of either group regarding alcohol use. The proportion of the homosexual population that problematically uses alcohol and drugs may well be substantially higher than in the nongay population (Fifield, DeChescenzo, & Latham, 1980). While the data are limited and of questionable reliability, Smith has commented that:

> "On the basis of information obtained from several researchers . . . it would seem that three out of every ten homosexuals are likely to experience significant difficulties as a result of alcohol abuse. In fact, the above percentages may actually be somewhat conservative, as most of them were based on self reports." (Smith, 1980, p. 92)

Extensive use of alcohol by people with AIDS in Belle Glade, Florida, is apparently well known (M.E. Whiteside, telephone communication, 1986) but is not part of the surveillance history used by CDC or other health care workers there. The question of drugs and alcohol exposure of hemophiliac people with AIDS and children with AIDS has not been investigated. However, the effects of alcohol on fetal immunity with decreased T-cells and T-cell function (Fetal Alcohol Syndrome) have been shown (Johnson, Knight, Mamer, & Steele, 1981). It has also been demonstrated that T-lymphocyte function in pregnant women who drink is suppressed (Madden, Donahoe, & Smith, 1984).

STATEMENT OF THE PROBLEM

Data are now available to show that a relationship between alcohol and drug usage and unsafe sex practices exists. In one study, 65% of gay people stated they used alcohol or recreational drugs before or while having sex, and 18% reported they were so drunk they would not drive a car (Research and Design Corp., 1985). Gay and bisexual men are very aware that they are more prone to have unsafe sex if they have been using alcohol or drugs (Room, 1985). However, it is not at all clear that IV drug users, hemophiliacs, and other HIV-positive individuals and their partners (who may be viremic and infectious) have the same degree of awareness as gay and bisexual men. It seems self-evident that efforts to educate the population of concern regarding the "disinhibiting" effect of drugs and alcohol, and the subsequent risky behavior that ensues, need to be made and evaluated.

The disinhibiting effects on behavior caused by alcohol and other drugs are well known and may possibly allow for more frequent and "dangerous" exposure to the probable causative virus of AIDS; however, the question of the effect of drugs and alcohol on the integrity of the immune system, either alone or in combination, has been investigated only sporadically and incompletely (Geokas, 1984).

In a recent symposium on alcohol and the immune system, a section on AIDS contained only four abstracts, none having to do with the clinical coexistence of alcoholism, chemical dependency, and AIDS or with basic investigations of susceptibility to AIDS relative to drug and alcohol use, acquisition of HIV infection during drug exposure (e.g., are drunk chimps more susceptible to HIV and AIDS than sober ones?), or progression from Aids-Related Complex (ARC) to AIDS as a potential consequence of chemical use (National Institute on Alcoholism and Alcohol Abuse, 1985).

The direct effects of drugs on the immune system have been intermittently studied. While no definite long-term effect on generalized immunity has been documented, suppression of normal lymphocyte function in acute phases of alcohol detoxification has been shown in some studies (Lundy et al., 1975; Watson et al., 1985). Atrophy of the thymus, which is so markedly impaired in AIDS, is the major source of T-cell lymphocyte populations and has been shown to occur in alcohol-fed rats (Tennebaum, Ruppert, St. Pierrer, & Greenbeyer, 1969). In addition, it has been demonstrated that lymphocyte function is suppressed by the presence of clinically observable alcohol concentrations (Glassman, Bennott, & Randall, 1985).

T-cell subset analysis in one sample reveals significantly fewer OKT4 (helper) cells in both IV and non-IV drug abusers than controls (Maayon et al., 1984). The correlation between use of nitrites and development of Kaposi's Sarcoma now seems to be much clearer (Mathur-Waugh, Mildaun, & Sehie, 1985). It has been known for many years that heavy alcohol use predisposes a person to certain infectious diseases, especially tuberculosis and klebsiella pneumonia, and also to less severe infections. The reasons for this are not clear but have been variously ascribed to poor white blood cell function (including suppression of lymphocytes), to polymorphonuclear cells, and to alteration of protein synthesis including immunoglobulins.

Whereas the HIV virus may not cause clinically apparent AIDS in most people who are infected with it, there is a strong coincidence of the appearance of AIDS and the use of chemical substances which not only cause disease in and of themselves but may be cofactors in the development of the full Acquired Immunodeficiency Syndrome. In addition, the frequent pattern among both people with AIDS and among many others as well is concomitant and conconcurrent use of multiple mood-altering substances. The combined effect of multiple drug use at the time of exposure to the HIV virus and the continued suppression of the immune system in the presence of the HIV virus may be enough to lead to the full-blown syndrome.

Other aspects of a possible association between AIDS and drugs which are of great interest and concern are (a) the altered effect that alcohol and drugs seem to have on people with AIDS and (b) the need for mood-altering medication in currently abstinent recovered alcoholics and addicts who develop AIDS. Health care workers in the field of substance abuse who also have experience with treating AIDS say that addicted AIDS patients seem to develop exceptional sensitivity to alcohol and drugs. People with AIDS commonly report, "I can't drink like I used to," and when withdrawal symptoms are present they seem more severe than in patients without AIDS. Nonaddictive alternatives for pain and anxiety need to be carefully developed, and professionals familiar with the problems of medication use of all kinds for recovered alcoholics and drug addicts should be part of the treatment team for such patients who also have AIDS. This is essential in order to evaluate medication and to avoid inappropriate withholding of medications as well.

RECOMMENDATIONS FOR TREATMENT PROFESSIONALS

At this point it should be clear why alcoholism and drug treatment professionals need to be involved with research treatment and policy formation regarding the AIDS epidemic, as inevitably they must be. The reasons include the following:

1. Alcohol and drugs may be cofactors in the acquisition, development, worsening, or transmission of AIDS.
2. Attention to individuals who are high risk for AIDS and are also ill with chemical dependency should become a very high priority of the A&D community.
3. People with AIDS, or HIV-positive individuals, may recognize their own need for chemical dependency treatment and seek it.
4. Intervention and treatment strategies for people with AIDS, ARC, HIV-positivity (or who are at risk for these conditions) and also have a concomitant substance use disorder are best devised and executed by, or in association with, alcoholism and drug treatment professionals.

Some specific recommendations are:

1. Inservice education on AIDS should be provided for all members of the treatment team. This should include all workers on the unit (including maintenance workers) and should occur regularly, with quarterly updates. Lack of transmission of the HIV virus by casual contact needs emphasis.
2. Counselors should become particularly proficient in discussing AIDS-related issues (e.g., fear of touching an IV drug user, or unwillingness to use a washing machine recently used by a gay man on the unit, or aversion to hugging an HIV-positive patient).
3. Entire treatment staff should examine internalized homophobia in themselves and in their patients, including their gay patients.
4. A regular lecture on medical aspects of AIDS should be included in every treatment program as part of the standard orientation to chemical dependency.
5. Treatment programs should form a liaison with medical personnel who are familiar with treatment of problems in AIDS and ARC and who have some knowledge of substance use disorder.
6. Intervention strategies for getting into treatment high-risk AIDS individuals who are also ill with substance use disorder should be devised and implemented, in cooperation with community groups which serve these at-risk populations. Special attention to the problem of intervening with IV drug users will be required.

CONCLUSION

Fear can easily drown out the voice of reason, which has little chance to develop in an environment of ignorance (Freud, 1952, p. 696). This is certainly true with regard to dealing with AIDS as described above. A growing knowledge of AIDS is necessary to change attitudes and to form reasonable policies and can best be acquired by cooperation among the various disciplines involved. The endeavors suggested here should not be left to medical, social service, or other professionals, any more than we now leave to any one professional group the treatment of other patients with chemical dependency. It is hoped that the response of the alcoholism and drug treatment community to this new challenge will be similar to those challenges in the past—that we will say, "We are responsible to see that appropriate care is provided."

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AIDS AND SHOOTING DRUGS

You don't have to be strung out to be exposed to the HIV - you can be exposed by shooting drugs only a few times. You don't have to use veins to be exposed, you can get the virus from skin popping, too.

It doesn't matter what drug you are shooting. The virus is passed in **DIRTY WORKS.** Paraphernalia that looks clean can be contaminated. The virus cannot be seen. People who sell needles and syringes sometimes re-wrap used works to look like new.

Needles (spikes), syringes, and other paraphernalia in shooting galleries are very dangerous. Sharing your works or using someone else's works is very dangerous.

NEVER SHARE YOUR WORKS, NOT EVEN WITH A CLOSE FRIEND OR LOVER!

Syringes, spikes, eye droppers, pacifiers, and other paraphernalia should be washed with soap and water and then soaked for 1/2 hour in fresh liquid chlorine bleach (like Clorox) that is mixed with water (1 part bleach, 9 parts water). This will kill the virus. You have to rinse everything very well after soaking. Glass syringes and metal needles can be boiled for 1/2 hour.

THE ONLY WAY TO BE REALLY SAFE IS TO NOT SHOOT DRUGS! If you can't stop on your own, get help. If you are strung out, get on a methadone program. If someone you care about is shooting drugs, help them get help. You could save a life!

SOURCE: G. Garr and G. Gee, "AIDS-Related Conditions: Screening for Populations at Risk", in AIDS: Concepts for Nursing Practice, edited by G. Gee and T. Moran. Williams & Wilkins Publishers, Baltimore, MD 1988.

per liter. Weight loss and polyneuropathy developed subsequently, and zidovudine (200 mg six times per day) was prescribed. Four weeks later the patient was admitted to our hospital because of a two-week history of fever, dyspnea, and neck pain. Physical examination revealed a temperature of 38.2°C, an elevated central venous pressure, cardiomegaly, dullness of the cardiac sounds, pericardial friction rubs, and atrial fibrillation. Examination of the lungs was unremarkable at admission, but pleural effusion and rales were later found over the left lung. The electrocardiogram demonstrated atrial fibrillation, a low-voltage pattern, and ST–T-segment elevation of the inferior and precordial leads. The echocardiogram showed pericardial effusion and an increased left ventricular end-diastolic dimension. The chest film showed enlargement of the cardiac silhouette, patchy infiltration in the posterobasal segment of the left lung, and a left-sided pleural effusion. *C. trachomatis* was isolated from the bronchoalveolar fluid by culture in HeLa-229 cells and identified by fluorescent monoclonal antibody (Syva, Palo Alto, Calif.). These antibodies do not cross-react with *C. psittaci*, including the TWAR strain.[3] Cytologic investigation for ***Pneumocystis carinii***, as well as bacterial and viral cultures of the bronchoalveolar fluid and the pericardial fluid, was negative. *C. trachomatis* could not be recovered from pericardial fluid obtained one day after treatment with doxycycline was started. In an immunofluorescent-antibody assay, the IgG titer against chlamydia was 1:1024 at admission, 1:512 after two weeks, and 1:256 after four weeks. Specific IgM was not detectable. Evacuation of the pericardial effusion by substernal puncture and treatment with doxycycline (100 mg per day for one month) resulted in a complete clinical recovery. There was no recurrence of the pericardial fluid, and the chest film at discharge showed no abnormalities.

Although *C. trachomatis* pneumonia is not considered to be an indicator disease for the acquired immunodeficiency syndrome,[4] it is logical to assume that our patient was predisposed to this infection because of his HIV infection. In addition to inducing the pneumonia, chlamydia could have caused the pericarditis in this patient.[5] The recognition of chlamydial infections in HIV-positive patients is important because of the seriousness of the condition, the specific diagnostic investigations required, and the therapeutic consequences.

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CHANGES IN NEEDLE SHARING AND SYRINGE CLEANING AMONG SAN FRANCISCO DRUG ABUSERS

To the Editor: Studies conducted from 1985 to 1987 indicated that most intravenous drug users in San Francisco were attempting to reduce their risk of infection with HIV by cleaning their syringes with bleach, but these studies found only small changes in the reported frequency of needle sharing.[1,2] Recent analyses of patient reports in our San Francisco drug-abuse clinic reveal considerable decreases in needle sharing as well.

All clients entering the outpatient heroin detoxification clinic of San Francisco General Hospital from 1986 to 1988 answered questions about the number of times they had shared needles in the previous month and the number of people who had shared each needle. To assess the change in such statistics over time, we selected all clinical admissions (n = 313) in June of each of the three years. The results are shown in Figure 1. The proportion of patients sharing needles decreased from 55 percent to 28 percent ($P<0.001$). However, the decrease is accounted for by patients reporting one needle-sharing partner, which decreased from 37 percent to 15 percent. The proportion of patients who reported sharing a needle with two or more partners decreased only 5 percent — from 18 percent in 1986 to 13 percent in 1988. In a multiple logistic regression analysis controlling for age, sex, race, and previous treatment, cocaine use was significantly ($P<0.05$) associated with needle sharing with multiple partners in the month before admission.

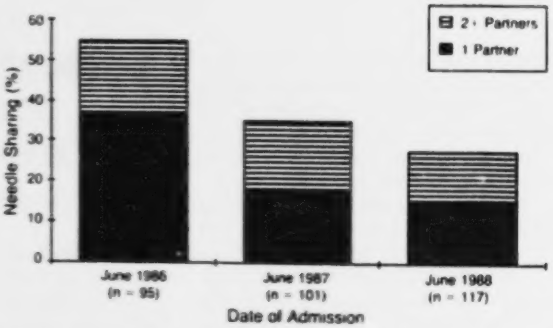

Figure 1. Needle Sharing in the Month before Patients Entered the Outpatient Clinic for Heroin Detoxification.

In addition, patients have reported using condoms in the syringe-cleaning process. The rubber plunger becomes stiff when the syringe is repeatedly sterilized with bleach. Several patients have reported lubricating the plunger by inserting it into the packet of a lubricated condom, thus restoring its smooth action.

The use of condoms to lubricate syringes may have some value if the lubricant contains sufficient nonoxynol 9 and provided it does not contribute to irritation or infection. This practice also provides drug users with a reason to carry condoms, eliminating one reason for not using them during sexual activity.

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GROUP B STREPTOCOCCAL VACCINE IN PREGNANT WOMEN

To the Editor: The report of Baker et al. (Nov. 3 issue)[1] regarding immunization of pregnant women as a strategy for preventing perinatal infections with group B streptococcus raises concern. The statement that "two thirds of infant infections are caused by serotype III strains that produce both early-onset and late-onset infections" is misleading. Early-onset infection with group B streptococcus has been defined as the clinical onset of illness within 48 hours after birth.[2] Two thirds of the affected infants are colonized with type Ia, Ib, or II strains.[3] Delayed-onset infection (occurring more than 48 hours after birth) is caused by Type III strains in almost 100 percent of cases.[3] The statement by Baker et al.[1] that two thirds of such infections in infants are caused by serotype III strains represents the summing of the data for the acute-onset and delayed-onset groups. I would submit that the lumping of these two groups is a mistake, since their pathogenesis differs markedly.[2]

Briefly Stated

Voluntary Testing for HIV Antibodies among Clients in Long-Term Substance-Abuse Treatment

Robert P. Galea, Benjamin F. Lewis, and Lori A. Baker

Acquired immune deficiency syndrome (AIDS) currently is among the foremost health concerns in the United States. Since the first cases of AIDS were reported in 1981, 56,212 cases of the disease have been reported to the Centers for Disease Control (CDC); consistently, one-fourth of those cases, or 13,881, have been diagnosed in individuals who abuse drugs intravenously.[1] Although sexually active homosexual and bisexual men continue to compose the largest group of individuals at risk for AIDS, totaling 66 percent of all reported cases, research suggests that intravenous drug abusers with human immunodeficiency virus (HIV) infection may be a critical link for the transmission of the virus to the general heterosexual population.[2] Fifty percent of 897 cases of pediatric AIDS have occurred in children who had at least one parent who abused intravenous drugs; 73 percent of the 2,233 cases of AIDS in heterosexuals involved transmission of HIV from an intravenous drug abuser to a spouse or lover.[3] The impact of intravenous drug abusers on the spread of AIDS to other heterosexuals may be greater in the future, especially because many drug abusers work as prostitutes to finance their addiction.[4]

Voluntary Testing

The threat of HIV infection, AIDS-related complex (ARC), and AIDS in members of this population pose special problems for residential substance-abuse treatment programs and other facilities that treat intravenous drug abusers. Although most treatment programs lack the medical facilities to care for clients with ARC or classic AIDS, it is likely that the increased availability of HIV antibody testing in such programs will reveal a significant percentage of HIV-positive, asymptomatic clients enrolled in substance abuse treatment. Currently, the rate of HIV seropositivity among intravenous drug abusers in metropolitan New York and northern New Jersey is between 50 and 60 percent.[5] While seropositivity rates for HIV vary in other parts of the country,[6] it is not unreasonable to assume that, in areas with numerous cases of HIV infection, ARC, or AIDS, one out of every two intravenous drug abusers receiving treatment already may have been exposed to HIV.[7]

Drug treatment professionals confronted with cases of asymptomatic HIV infection in their client populations may need to consider, first and foremost, infection control policies. Such policies protect HIV-negative clients and staff and, perhaps more critically, HIV-positive clients, who may be more susceptible to a variety of infections due to their compromised immune status.

In addition, there are numerous psychosocial issues involved in the treatment of intravenous drug abusers with asymptomatic HIV infection. The diagnosis of HIV infection is, by its very nature, ambiguous, because knowledge is still limited regarding the likelihood of progression from HIV infection to ARC or AIDS. Estimates on the likelihood of developing AIDS in HIV-infected individuals vary from 20 to 60 percent. One study demonstrated that 36 percent of subjects with HIV infection developed AIDS over a period of 72 months.[8] The HIV-positive diagnosis, therefore, may be particularly anxiety provoking, and may undercut the commitment of intravenous drug abusers to remain in treatment. Clearly, it is critical that HIV-positive clients remain in treatment, because a return to drug abuse is likely to lead to transmission of the virus to others, as well as to poor health and further exposures to HIV for the seropositive individual—two factors that might exacerbate the course of the illness.[9]

In response to a growing awareness of the spread of HIV among intravenous drug abusers, a comprehensive substance-abuse treatment program located in Westboro and Worcester, Massachusetts began voluntary HIV testing of clients in its residential, detoxification, and methadone services facilities as part of an ongoing effort to integrate AIDS education and risk assessment into the overall treatment program. Ninety-eight percent of clients undergoing treatment request HIV antibody testing, with a current seropositivity rate of approximately 18 percent.

To ascertain the impact of an HIV-positive test result on client attitudes and commitment to treatment, the authors instituted a six-week series of discussion groups for seropositive clients receiving treatment in the program's residential facility. Although the purpose of the group was informational rather than therapeutic, it also served as a support group for the HIV-positive clients, who were still a minority in the client population. Clients were queried regarding their initial reaction to the HIV-positive test result, attitudes toward health issues in general and HIV infection in particular, the impact of the positive result on relationships with spouses or significant others, their views about the relevance of substance abuse treatment, and their fears of physical and social decline and ostracism surrounding the HIV-positive test result. Clients also were asked their opinions as to the potential efficacy of various modes of education for drug abusers "on the street" regarding AIDS prevention, such as the distribution of clean needles and bleach, and community outreach efforts.

HIV-Positive Discussion Group

As of summer 1987, seven clients in the residential program tested positive for exposure to HIV; all but one are asymptomatic. All of the clients had entered treatment before testing positive and voluntarily decided to take the HIV antibody test when it was made available by the program. Of the seven, one left treatment within a month after a positive HIV test result and fatally overdosed shortly thereafter. Another of the seven HIV-positive clients worked full-time outside the program, and was unable to participate in the group.

The five clients who participated had been in treatment and aware of their HIV-positive status for varying amounts of time. One client, having tested positive for HIV 10 months earlier, had completed the residential component of the program and was receiving treatment as an outpatient; another had been in treatment for 10 months, and had tested positive for HIV exposure six months before inception of the discussion group; two had been in treatment for four months and aware of their positive test result for three months; and one had been in treatment for seven months but knew of the HIV-positive diagnosis for only one month. Three of the clients were male, including one Hispanic; two were female, including one black. All clients were native to the Boston–Worcester areas, with the exception of one client, who was from the metropolitan New York area.

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Client Reactions: Testing Positive

At least two of the five clients in the discussion group cited anxiety regarding AIDS as a significant factor in choosing to enter substance abuse treatment. Both of these clients reported virtually certain exposure to the virus—one through a sexual relationship with an individual subsequently diagnosed with AIDS, the other through the sharing of needles with such an individual. Despite their knowledge of their risk for HIV exposure, however, none of the clients had been tested for AIDS before entering treatment.

All of the clients reported denial and anxiety as their initial reaction to the HIV-positive test result. Although they knew their behavior placed them at risk for AIDS, some group members reported they felt they were immune to AIDS, as well as to hepatitis (another disease common to intravenous drug abusers).

Two of the five clients reported a sense of "my time being limited," even though neither had experienced any symptoms of ARC or AIDS. Also mentioned relative to time limitation was the desire to spend more time with family members or, alternatively, "to run—to be out around people who didn't know me."

The clients who had been aware of their positive test result for the longest periods of time (10 months and six months) reported more feelings of depression, health-related anxiety, and anger. For example, they were more likely to worry that the symptoms of a common illness, such as a cold, might signify the start of an ARC- or AIDS-related infection, although such symptoms would have been unremarkable before the HIV-positive test. Their feelings of anger were sometimes directed toward health-care providers who were unable to cure AIDS, or to answer their questions adequately. One client said she felt that "[her] life is being toyed with."

Although only one of the clients in the group had experienced any symptoms of ARC or AIDS, and none was diagnosed as having either ARC or AIDS, their reactions to the HIV-positive test result mirror reactions found in psychiatric consultations with patients diagnosed with AIDS These reactions include depression, anxiety, feelings of being "experimented on," and a sense of "unfinished business" with family and friends.[10] Additionally, depression among HIV-positive but asymptomatic clients has been associated with the effects of the AIDS virus on the central nervous system were thought to be before the development of opportunistic infections.[11]

Client Attitudes toward Health

Intravenous drug abusers have been noted often for their lack of concern with health, both their own and others.[12] Although the addicts' response to HIV has begun to contradict this assumption,[13] it generally is true that drug abusers often are in poor health because of their addiction. They also are accustomed to observing poor health in members of the social network within which they may share needles. Several of the early symptoms of ARC and AIDS, such as lymphadenopathy, weight loss, fatigue, unexplained fevers, and night sweats, also are common among intravenous drug abusers who do not test positive for exposure to HIV.[14] The indifference of intravenous drug abusers toward health issues was well-illustrated by one of the clients in the HIV-positive group, who indicated that he had shared needles with his sister before entering treatment, despite the fact that she was ill and he suspected she might have AIDS—a suspicion that was confirmed later. Another client admitted that she would have "picked works up off the ground and used them" if she were desperate to "shoot up," despite the risk of exposure to HIV.

Because of the positive test result for exposure to HIV, health became a major concern for all of the clients in the group. Certain attitudes toward health were associated with the length of time clients had been aware of the positive diagnosis. For example, those who most recently had tested positive were concerned especially with issues such as exercising and eating right; they indicated, in particular, the hope that better health habits might delay or prevent the development of ARC or AIDS. These clients initiated personal fitness programs, such as jogging, exercising, or giving up smoking. They also reported instances of "self-testing" their endurance—working harder or staying up later than usual. "When I'm sick I won't lay in bed. I have to get up and keep moving—I'm not going to slack off," one of the clients noted.

The client who had tested positive six months earlier, while acknowledging that he had passed through a stage of self-testing, said he no longer tended to test the limits of his health. Rather, he had begun to take special precautions to guard his health, such as eating well and getting eight hours of sleep every night. Rather than pushing himself, when he felt sick he was likely to rest.

A focus on anxiety and depression regarding specific symptoms was typified by the one client, a female, who had tested positive 10 months earlier. Her depression may have been exacerbated by a long series of infections and poor health, which had, nonetheless, not been diagnosed as ARC or AIDS Unlike the other clients, she often seeme preoccupied with death as a result of HIV infection, and she was less motivated to pursue healthful changes in exercise and diet. She reported being tired of people urging her to push herself to be more active and less depressed.

Significant Others

The increased concern with health extended to the spouses, lovers, and friends of the HIV-positive clients. Informing spouses and lovers of the HIV-positive diagnosis was a major issue for several members of the group, and others also spoke of the difficulty of contacting persons with whom they shared needles whom they also might have exposed to the virus.

Although the clients were receptive to information about safe sex, actual implementation of safe sex precautions, such as use of condoms, was more ambiguous. Male clients admitted to feeling uncomfortable with the use of condoms—an especially major issue for group members who had progressed in treatment to the point where they could socialize outside the program. One of the female clients admitted to the group that she had sexual intercourse with her boyfriend and did not insist on safe sex precautions despite her longstanding knowledge of he HIV infection. The reluctance of intravenous drug abusers to alter their sexual behavior has been noted before,[15] along with the observation that they may be more likely to change their behaviors concerning sharing and sterilizing needles than to use safe sex measures.

Clients often mentioned guilt feelings associated with the possibility that they could have transmitted HIV to others. The attitude of family members also was problematic for some group members. Those who already had been estranged from parents or spouses because of their drug abuse feared further rejection because of the positive test for HIV exposure. In general, the level of knowledge about AIDS was lower among clients' family members than among their peers and counselors in the treatment community, with concurrently higher levels of prejudice and fear. Clients spoke of having to educate members of their family about HIV transmission, often at the same time that they told parents or spouses about their own positive test result.

In fact, such fears of rejection and abandonment are realistic ones. Previous observations have shown that HIV seropositive individuals, as well as those with ARC or AIDS, suffer from a considerable degree o social isolation.[16]

Public Reactions to Testing HIV Positive

Clients' concerns with the negative reactions of others to their HIV-positive status extended beyond spouses and families to include less intimate peers—for example, peers within the drug treatment program, co-workers, and, more broadly, society in general. Their comments indicated they were well aware of the prejudice, hostility, and rejection they might face outside of the treatment program.

Even within the program, the clients mentioned some negative reactions to their HIV-positive status, although the treatment community in general was characterized as supportive. Sometimes, clients mentioned that new admissions to the program were hostile about interacting or sharing sleeping quarters with them, because of their HIV-positive status. They felt like they were "polka-dotted," (that is, different from their peers). Two clients said that their peers made it difficult for them to feel sick—for example, if they stayed in bed to recover from a cold, they were accused of being hypochondriacs or "wanting to be babied" because of their positive test. Another client mentioned being aware of "buried attitudes" in the program that made him feel awkward and oppressed about certain individuals. However, all of the clients also mentioned demonstrations of support from both their peers and staff members that made the residential program a safer environment than the outside world.

Those clients who worked or had other contact with individuals outside the residential program were acutely aware of perceived rejections based on their HIV-positive status. One client, for example, reported that nurses at a local hospital wore gloves to give her a chest X ray—an unnecessary precaution. Another client who participated with the authors in an AIDS conference observed a conference sponsor taking special precautions to dispose of a can of soda from which the client had been drinking. Such instances contributed to a sense of ostracism and feeling different from others regarding their HIV-positive test.

Client's Views: The Value of Treatment

High rates of recidivism are common in all modalities of substance abuse treatment; this is especially true of long-term residential treatment. Observation of dropout rates in long-term residential therapeutic communities has shown six month retention rates of between 25 and 30 percent, with the greatest rate of dropout within the first three months.[17] At this particular treatment program, between 50 and 60 percent of all clients admitted to the long-term residential program leave treatment within the first two months. The percentage of dropouts was significantly smaller among HIV-positive clients (14 percent versus 60 percent).

Clients in the HIV-positive group verbalized a high degree of commitment to treatment; their addiction was perceived as more dangerous in the context of their HIV seropositivity. Although they sometimes admitted feelings of discouragement about remaining in treatment, they characterized a return to drug abuse as suicidal; all believed that they would develop AIDS within a few months if they returned to their previous lifestyle.

For this first group of clients, a positive test was a strong motivator for staying in treatment. Group members commented that "I needed to know I tested positive to go through this program," or "If I hadn't tested positive, I would probably manipulate myself into going on a few more 'runs.' "

Stopping the Spread of AIDS: Client Opinions

Methods of slowing the spread of HIV among intravenous drug abusers have been the subject of considerable public debate. One option in particular, the dispensing of free, clean needles to lessen the sharing of needles among addicts, has been regarded as controversial because it appears to encourage drug abuse.[18] Other methods, such as outreach programs to teach drug abusers how to sterilize their works, are less controversial. The clients in the HIV-positive group were asked their opinions on the potential effectiveness of both methods to slow the transmission of HIV among intravenous drug abusers.

The sharing of needles has been characterized as a ritual form of deeply ingrained social interaction that is important to the drug abusing subculture.[19] If so, the sharing of needles may be difficult to discourage, even with the availability of free needles. However, clients in the discussion group denied a strong social motivation for sharing needles. Rather, they said the sharing of needles is common because addicts are reluctant to spend their drug money to purchase new needles. In fact, they said, the sharing of "works" is disliked by most addicts because it necessitates a period of waiting before they can "shoot up." Free, clean needles, they said, probably would be utilized by addicts, because the waiting is eliminated.

Clients also were enthusiastic about community outreach education programs and the distribution of bleach to addicts "on the street." Several said they would be willing to participate as educators in such a program, especially in neighborhoods with which they are familiar.

Discussion

Among this small sample of clients, the positive test for exposure to HIV enhanced, rather than undercut, the effectiveness of long-term residential substance abuse treatment. This enhancement is manifested most clearly in the low drop-out rate among HIV-positive clients as contrasted with the general client population, especially during the first three months of treatment, when drop-out rates are highest. Other obvious behavioral changes associated with the HIV-positive test result included concern for health and involvement in and commitment to the day-to-day workings of the therapeutic milieu—such as leading educational seminars, establishing discussion groups, and participating in the orientation of new clients. The HIV-positive clients also expressed an enhanced concern for the health of their loved ones, guilt associated with the possibility of having transmitted HIV either sexually or through the sharing of needles, and a transition in values regarding their responsibilities toward their families and themselves. In discussions with these clients, the authors discerned a dialectic of "morality vs. mortality"—activities deemed good by society, such as work, interaction with the family, health-promoting activities, and educating or helping others were regarded by the clients as part of an overall life-style change capable of delaying or altogether preventing the progression of their HIV infection to ARC or AIDS. The ambiguity within the medical profession concerning the meaning of exposure to HIV bolsters the hope that such a change in life-style may be a significant factor in the outcome of infection with HIV.

The conscious sense of the clients' change in values, while beneficial to the continuation of their treatment, also served to mask partially the feelings of fear and anxiety caused by their HIV-positive status. Clearly, the clients' comments showed that they were aware of the difficulties they would face once outside the therapeutic community, including possible physical illness, unemployment, and rejection by spouses or families. Their investment in the structured activities and supportive social networks of the program allowed them simultaneously to deny and positively channel some of their fears regarding HIV, ARC, and AIDS.

Although the results of discussions with a small group of HIV-positive clients are not generalizable to the overall population of HIV seropositive intravenous drug abusers

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undergoing long-term residential treatment, the attitudes of these clients do indicate that testing for exposure to HIV among members of this population may prove beneficial to treatment outcome. However, such testing should be implemented within treatment settings where knowledge about HIV has been disseminated among staff and clients to allow a supportive reaction to the presence of HIV-positive individuals. It also is important that clients be provided with intensive pre- and posttest counseling and access to support groups throughout the course of their treatment.

The comments of these clients support the emerging opinion among researchers that intravenous drug abusers are receptive to AIDS education and to the use of simple procedures for the sterilization of shared needles. However, members of this group were reluctant to discuss and implement safe sex precautions. Given the critical role played by intravenous drug abusers in the heterosexual transmission of HIV, education to enhance changes in sexual behavior must be implemented in conjunction with that emphasizing the sterilization of drug paraphernalia.

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TREATMENT OPTIONS AND REFERRAL

Habit is habit and not to be flung out of the window by any man, but coaxed downstairs a step at a time. - Mark Twain

Distinguishing *use* from *abuse* from *addiction* can be very difficult and is not recommended or should not be assumed by looks, demeanor, etc. The safest approach is to offer referral to everyone:

Are you interested in learning of your different treatment choices?

If no: Here's a name and number you can call if you change your mind or if you know a friend who could use help.

If yes: Here's a name and number you can call to discuss your choices.

Reminder to everyone: Getting help for alcohol or other drug difficulties takes an extended effort. Plan on spending several weeks or more finding out about and arranging to start your preferred program. Self-help groups (AA, NA, CA, HIVIES, etc.) have no waiting period and have open participation for those looking for help.

Try this process yourself to get a feeling for the frustration tolerance necessary for success, cultivate names as well as numbers (giving a name makes for a more successful referral). Be sure to check out the programs' readiness for HIV-related issues!

Types of treatment available (depends on use, locale, funding, etc.):

- Inpatient treatment or detoxification (medical or social setting)- Therapeutic community (live in)- Outpatient - methadone (for opiate addicts), drug-free,or drug-assisted- Intensive outpatient (day (or evening) treatment)- Drug specific treatment- No charge, sliding fee, third party or "self" pay

To see what is in your area ask around or let your fingers do the walking. Remember it will take some digging to turn up all treatment options in your area.

Dan Bigg, CCSAC HIV Consultation and Training Service (708) 724-3832

ALCOHOL AND OTHER DRUG USE: ASSOCIATIONS WITH HIV INFECTION

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WHAT IS YOUR ROLE IN THE TESTING AND COUNSELING PROCESS?

WHEN TEST IS DONE IN YOUR FACILITY?

WHERE IS CONFIRMATORY TEST DONE?

HOW LONG FOR RESULTS?

WHO TO CONTACT IN YOUR LAB?

HOW ARE TEST RESULTS HANDLED?

WHAT IS YOUR HOSPITAL POLICY ON TESTING,COUNSELING, INFORMING AND DISCLOSURES?

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SEROLOGIC TESTS FOR HUMAN IMMUNODEFICIENCY VIRUS (HIV)

Alfred J. Saah, M.D., M.P.H.

Enzyme-linked immunosorbent assays (ELISA) to detect antibody to human immunodeficiency virus (HIV) have been marketed by seven manufacturers. The ELISA is used to screen blood products, for epidemiologic studies, and for clinical purposes. Repeated reactivity requires confirmation by a second assay such as the Western blot test.

In the latter test HIV antigens are separated electrophoretically and the ELISA-reactive serum is tested against all of these separated antigens. Clear reactivity to certain virus antigens indicates true infection with HIV. Other confirmatory tests are not as well established or as readily performed by most laboratories.

Synthetic antigens that may prove useful as screening or confirmatory reagents are being developed, as is a system to reliably measure HIV antigen in serum or plasma.

The acquired immunodeficiency syndrome (AIDS) was first described in June 1981.[1] The AIDS retrovirus was described in reports from France[2] and the United States[3]; in this report, it is referred to as the human immunodeficiency virus (HIV).[4] A retrovirus is so named because it synthesizes DNA from its RNA genome, a reversal of the normal process of transcription. This synthesis is catalyzed by the enzyme, reverse transcriptase.

An enzyme-linked immunosorbent assay (ELISA) was developed to test serum or plasma for antibodies to the retrovirus[5] and was licensed in March 1985 to screen blood donors for such antibodies.[6] This article describes the uses of the HIV ELISA as a screening and clinical tool, reviews various assays that are used as confirmatory tests, describes the next generation of serologic tests, and discusses the prospects for an effective antigen detection test.

The ELISA Screening Test

The ELISA is the most widely used serologic test for antibodies to HIV in serum or plasma. It is used for clinical diagnosis, to screen blood and blood products,[7] for epidemiologic studies,[8-12] and to test individuals who believe that they might be infected with HIV.[13] As of January 1987, seven manufacturers have been licensed by the U.S. Food and Drug Administration to market HIV ELISA kits (Abbott Laboratories; Cellular Products, Inc.; E.I. du Pont de Nemours & Company; ElectroNucleonics, Inc.; Genetic Systems; Organon Inc.; and Ortho Diagnostic Systems, Inc.).

Like other serologic tests, the ELISA indicates the occurrence of past infection. However, individuals with confirmed test results are presumed to be currently infected and capable of transmitting infection through blood or sexual contact. The ELISA cannot predict which asymptomatically infected individuals will develop AIDS. There are indications that the antibody level decreases as disease progresses,[8,14,15] but the variation is too great to be useful clinically.

Method

The ELISA uses disrupted virus grown in tissue culture. The viral antigens are placed on beads or in plastic microtiter wells. The serum specimen is incubated with the antigens and if antibody attaches to any component in the well or on the bead, it is detected by a second antibody that detects IgG antibodies. The second antibody is labeled so that a subsequent enzymatic reaction produces a color that is proportional to the amount of human IgG present. The usefulness of assays for IgM, eg, in neonates, is unclear. The reactivity of a serum specimen, ie, its optical density, is usually compared to that of positive and negative control specimens tested simultaneously. Each test kit has a somewhat different method of determining the "cutoff" or "threshold" value above which a positive reaction is defined. The cutoff for each kit has been selected to optimize its sensitivity and specificity.

The ELISA is designed to be sensitive because its primary purpose has been to prevent contaminated blood from being used for transfusion.[7] In blood banking operations and clinical laboratories, serums are screened initially as single specimens. If the test result is positive, duplicate tests (two wells) are repeated from the same serum specimen. If *one* of the two tests is positive, the serum specimen is considered positive by ELISA; hence the term "repeatably reactive" is often used in place of "positive." If both repeat tests are negative, the serum specimen is reported to be negative by ELISA. Therefore, for an individual to be reported as positive by ELISA, at least two of three tests on the same serum specimen should have reacted positively. The antigens in the test well also contain antigens from the cell lines (H9 or CEM) used to grow the virus and other reagents that may cause a nonspecific reaction and make the test result appear to be positive.[16,17] Therefore, it is necessary to confirm all positive specimens using another, more virus-specific test, usually the Western blot (see page 12).

Performance Characteristics

The ELISA detects *antibody* to the HIV. It does not detect viral *antigens* and, thus, cannot detect infection in its earliest stages, ie, before antibody is formed. Transmission by blood transfusion has been documented at the preantibody stage.[18] It appears that antibody rises to detectable levels 4 to 12 weeks after infection occurs.[19] However, prolonged seronegativity has been reported.[20] The duration of such antibody-negative status is unknown. Self-deferral from blood donation by members of high-risk groups continues to be an important means of preventing transfusion-associated AIDS.[21]

The prevalence of antibody-positive individuals determines the types of

Source: AMA AIDS Information on AIDS for the [illegible] false results that are produced.[22-24] If the ELISA identifies approximately 0.25% of donated blood as repeatably reactive and the Western blot confirms HIV infection in 0.1% or 1 per 1,000, then for every 10 million individuals in the general U.S. population that are screened, approximately 25,000 (0.25%) will be repeatably reactive by ELISA, but only 10,000 (0.1%) will be confirmed by Western blot. Therefore, in the general population where antibody prevalence is very low, a repeatably reactive ELISA has poor predictive value. However, in a high-risk population, where prevalence of HIV infection is as high as 30% to 70%, a positive ELISA is almost always confirmed by Western blot, thus giving a very high positive predictive value. (Confirmation by Western blot is nonetheless necessary.)

All of the licensed ELISA kits have high sensitivity and specificity values, yet their performance necessarily reflects the prevalence of HIV infection in a given population, thus making the kits predictably inexact. In populations with very low prevalence of HIV infection, false-positive ELISA reactions will predominate; in populations with high seroprevalence, false-negative reactions will be seen more commonly.

Although the licensed ELISA kits have very good sensitivity in well-established infection, sensitivity during the earliest phases of antibody production may be low.[25] Published comparisons[26,27] should be reviewed often by laboratories to identify the test kit(s) that best suit their needs.

Confirmatory Tests

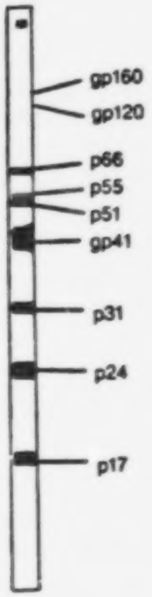
The Western Blot

In the Western blot, purified virus antigens are separated by electrophoresis and the serologic test is performed on the separated virus antigens. In this way, one can determine whether the antibody that reacts in the ELISA is specific for HIV virus antigens or cross-reacts with other nonviral components of the ELISA system. The antigens in the Western blot are HIV proteins or glycoproteins of varying molecular weight. The antigens are designated as "p" for protein and "gp" for glycoprotein with a number that indicates their molecular weight in thousands of daltons (kd). Therefore, a band designated gp41 is a glycoprotein of molecular weight 41,000 daltons. The Western blot is used to confirm seroreactivity to the virus in the ELISA.

The Western blot is usually interpreted with the naked eye. When bands are weakly reactive, the interpretation is highly subjective. Because of this subjectivity and because standardization of reagents is technically difficult, licensure has been delayed. Many of the technical issues now have been overcome and the Western blot probably will be licensed in the near future.

The figure shows a Western blot with a characteristic positive band pattern. Like the ELISA, the Western blot measures IgG antibodies. Important bands include p24 (a core protein of the virus) and gp41, gp120, and gp160 (envelope glycoproteins of the virus). Most laboratories are unwilling to interpret a blot as positive if it does not demonstrate reactivity to at least two bands that include one or more envelope antigens. The diagnostic specificity of the Western blot may improve if reactivity to endonuclease (p31) and reverse transcriptase (p51, p66) are considered in defining a positive blot. A national standard for Western blot interpretation should be established.

Reactivity to core antigens exclusively may represent early infection with HIV or another retrovirus or may represent a poorly understood cross-reaction. Another serum specimen should be obtained from the patient in four to six months and the Western blot repeated. If the patient is truly infected with HIV, this interval should allow antienvelope antibody to become detectable. The Western blot should be interpreted cautiously; in equivocally reactive specimens, testing the uninfected cell line against the patient's serum may prove helpful but frequently fails to identify the source of nonspecific reactivity. Another test, known as the radioimmunoprecipitation assay (RIPA), may be helpful when the Western blot is equivocal.



Legend

A highly reactive serum showing many bands by Western blot. Major bands include p24 (core antigen) and gp41 and gp160 (envelope antigens). p31 (an endonuclease) and p51 and p66 (reverse transcriptase) may make interpretation more specific. (Photo: Biotech Research Laboratories)

The RIPA

The RIPA is a research tool[28] that is expensive, requires radioisotopes and expertise for interpretation, and is labor intensive. The assay reacts serum with an HIV-infected cell lysate as substrate for immunoprecipitation and subsequent electrophoresis. The cell lysate is rich in relatively undenatured HIV envelope antigens and, therefore, is useful in defining antigenic differences among various human and simian immunodeficiency viruses.[29] The RIPA appears to be more sensitive than the Western blot for the higher molecular weight envelope antigens (gp120 and gp160).

The Indirect Immunofluorescence Assay

The indirect immunofluorescence assay (IFA) is an effective confirmatory test in experienced hands.[30,31] In fact, the California State Health and other state health departments are using the IFA as their confirmatory test at the HIV counseling and testing sites. With this test, serum reacts with HIV-infected cells from tissue culture. Antibodies to HIV antigens attach to many sites within the infected cells, and the attached antibody is detected with fluorescein-labeled goat antihuman globulin and read under a fluorescent microscope. Positive specimens are usually easily identified because of the bright fluorescence in a given proportion of cells. The IFA has not been widely utilized because of the test's subjective interpretation and the need for uninfected cells to absorb nonspecifically reactive serums. Refinements of the IFA also have been reported.[32]

"Second generation" Screening and Confirmatory Assays

Second generation assays use synthetic peptides instead of native virus to test for antibody. Many synthetic core and envelope antigens are being tested to identify HIV antibody-positive serums. Such research not only identifies potential antigens that may prove useful as diagnostic reagents, but also helps to identify the regions of the various antigens that appear most immunogenic.[33] The latter has great importance in the search for an effective vaccine. No synthetic antigen has been tested widely enough to forecast its usefulness clinically in either a screening or a confirmatory assay.

Antigen Detection Tests

Viral Antigen Capture

Monoclonal or polyclonal antibodies are available for use in radioimmunoassays or ELISAs to detect p24 antigen in supernatant fluid from HIV cultures.[34,35] The monoclonal or polyclonal antibodies act by capturing viral p24 antigen. In this type of ELISA, a second labeled antibody is added to detect the captured antigen and produce a color enzymatically. The commercially available antigen detection assays appear to be more sensitive than reverse transcriptase assays in identifying positive cultures.

Attempts have been made to use the p24 antigen assays in human serum or plasma for direct measurement of viral antigen. When such p24 assays are used this way, endogenous antibody to p24 has been found to interfere with the assay to a great extent. Therefore, the usefulness of such assays in screening blood donors is unknown at this time. Another use may be in natural history studies of individuals who are at risk of seroconversion. Such studies would allow investigators to determine the evolution of very early infection and thus make the job of identifying early infection more feasible.

In situ Hybridization

In situ hybridization identifies HIV-produced RNA or DNA using a radiolabeled probe.[36] A probe specifically identifies cells with multiple copies of particular nucleic acid sequences because it is a complementary RNA or DNA sequence that attaches (hybridizes) to virally produced RNA or DNA. Such techniques have not gained wide acceptance because of the small number of peripheral blood leukocytes that are identifiably infected. A recent report of the diagnosis of HIV infection in a newborn by in situ hybridization to cultured peripheral blood lymphocytes raises hope that such techniques will be useful in the neonate.[37]

The standard assays for antibody are not useful in perinatal HIV infection because passively transferred IgG from infected mothers makes neonates serologically reactive, although they are not necessarily infected. Serial Western blot assays may prove helpful by identifying new bands.[38] Reliable and standardized assays for IgM antibodies are still under development.[39,40] In situ hybridization techniques remain a research tool at present.

Uses of Serologic Tests

Serologic testing for HIV is generally used (1) for screening a given population group, such as potential blood donors, or (2) for diagnosis. In the latter instance, the use and meaning of the ELISA and Western blot tests should be discussed with the patient during history taking and subsequent evaluation. The results of such testing should be a part of the patient's medical record, but confidentiality is important. In research protocols, confidentiality is doubly important because many subjects may be infected with HIV but are healthy and their voluntary participation may not benefit them directly. It should be noted that nothing prevents the clinician from performing HIV testing under a coding scheme if anonymity is requested; such a scheme may produce devastating errors in a hospital laboratory setting. Such procedures would ensure a higher degree of confidentiality, but are more appropriate in an HIV counseling and testing site (formerly known as alternate test sites) rather than a hospital laboratory. A positive result would impart to the physician the responsibility to counsel the patient (see below).

The use of these tests as a screening device, eg, in the blood bank, requires notifying the party to be screened that the testing will be done, and that if positive results are confirmed, counseling and medical referral will be provided. In HIV counseling and testing sites, which are provided through state health departments to allow interested persons to determine their serologic HIV status anonymously and without attempting to donate blood, counseling is provided both before and after testing regardless of the test result. Those attending a counseling and testing site either belong to a high-risk group or think that they may have been exposed. These individuals should be counseled on methods to reduce their risk of infection if they are seronegative, while those who test positive need to know the practical implications (see below).

In the clinical setting, an HIV-positive result is useful in that it may lead the physician to include an AIDS-related condition in the differential diagnosis and to take an aggressive approach to the patient's illness if necessary. Individuals who are identified as positive also require careful counseling.[6,41-43]

Interpretation of Test Results

If the ELISA is negative, a Western blot is usually not done. Blood from ELISA-negative individuals who do not belong to any risk groups may be used for transfusion. Individuals from high-risk groups should be notified that a negative ELISA test does not carry the same degree of confidence as in low-risk individuals.

If the ELISA is positive and is confirmed by Western blot or IFA, then the individual has been infected with HIV.

If the ELISA is positive and the Western blot is completely negative, the patient's blood should, nevertheless, *not* be used for transfusion, although re-entry into the blood donor population may be possible in the future. Such a patient (donor) is probably not infected with HIV. If the Western blot and/or IFA is equivocal, the infection status with HIV is unknown and the Western blot should be repeated on a specimen obtained in four to six months.

Counseling

Information to be communicated to patients with antibody to HIV should include at least the following:

1. The infection is persistent, probably for life, and a certain proportion of those affected will develop AIDS. Approximately 35% of HIV antibody-positive individuals developed AIDS over six to eight years,[44] but having a positive antibody test does not mean that the patient has AIDS.

2. It is not possible to predict who among seropositive individuals will develop AIDS or show clinical symptoms.

3. Antibody-positive persons are potentially infectious to others by sexual exposure, by sharing drug injection paraphernalia, by childbearing, or by donating blood, semen, or body organs.

4. Antibody-positive persons should practice what has come to be known as "safe sex." In the absence of celibacy, this usually means using a condom routinely when having sexual intercourse. Preventing perinatal HIV infection requires that adequate birth control measures be employed.

Underlying all of the above measures for controlling the spread of HIV infection is notification of all individuals who are HIV antibody-positive, providing them with the above information, and being available to answer questions. Information for counseling seropositive individuals is available through state or local health departments and from a number of AIDS information organizations. Antibody-positive individuals should also be encouraged to notify their sexual partners, so that the risk for further transmission may be reduced. The responsibility to notify known sexual partners may fall to the physician if an antibody-positive person refuses to do so, but this area is extremely complex and unsettled. In some jurisdictions, seropositive individuals must be reported to the health department. The advisability of mandatory screening, as in the prenatal setting or for marriage license application, will continue to be debated. The ultimate purpose of such screening is to reduce the incidence of infection by reducing transmission through changes in behavior.

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HIV TEST RESULTS

ELISA (-) (Could be a False Negative If In Window Period)	ELISA (+) WESTERN BLOT (-) or IFA (-) (False Positive)
ELISA (+) WESTERN BLOT (equivocal) or IFA (equivocal)	ELISA (+) WESTERN BLOT (+) or IFA (+) (POSITIVE)

POSITIVE - INFECTED FOR LIFE AND INFECTIOUS TO OTHERS
SHOULD NOT DONATE BLOOD DOES NOT PROTECT AGAINST
FUTURE INFECTION

DISCLOSING POSITIVE HIV ANTIBODY STATUS TO SPOUSE OR SEXUAL PARTNERS: ETHICAL AND LEGAL CONSIDERATIONS

John A. Dougherty, Ph.D., Lexington VAMC, 13 Dec 1989

Sources: VHS&RA Circulars 10-88-134 & 151, and their Supplements, which interpret PL100-322; & other ethics sources concerning health professional disclosure.

Introduction:

It is impossible for Congress to write laws and for the DVA to interpret and implement congressional intent in a manner that clearly anticipates all situations counselors will encounter in making a decision whether to disclose a veteran's positive antibody status to a spouse or sexual partners. Therefore, individual judgment guided by an understanding of the relevant ethical and legal concepts will be necessary in many situations. Rather than specifying specific courses of action in its Circulars, the DVA has wisely emphasized the application of individual judgment by the counselor in the context of two primary and conflicting ethical concepts: confidentiality of the veteran and protection of the health of spouses and sexual partners. Also, because the law permits but does not mandate disclosure, the counselor has considerable latitude in making decisions that balance the individual health needs and rights of veterans and their spouses. With this flexibility, however, comes uncertainty and added responsibility for the counselor. The following writing is an attempt to explore, elucidate, and raise questions about the ethical and legal concepts surrounding disclosure.

1. Central Concepts Related to Disclosure

a. Primary purpose of disclosure is to protect the health of spouses and sexual partners.
b. Disclosure by health professional is limited to positive antibody test results.
c. Disclosure by health professionals is permitted, not required.
d. As the authorization for disclosure of seropositive results to spouse or sexual partner is explained in pre-test counseling and is on the consent form signed by the veteran before HIV antibody testing, there is implied consent for counselor's disclosure of seropositive status under certain conditions specified in the Circulars.
e. Disclosure should occur only when necessary to protect the health of the spouse/sexual partner as judged by the health professional, and when the counselor has a reasonable belief that the veteran has not voluntarily disclosed, and only after reasonable efforts have been made to counsel and assist the veteran to voluntarily disclose.

f. The foreseeability of harm to third parties is an important implied concept and involves the judgment that the veteran continues to place spouse/sexual partners at risk.
g. Spouses and sexual partners are treated differently with respect to the way in which they are identified.
h. The primary ethical conflict is between protection of health of third parties and the confidentiality of the veteran.
i. Other important ethical considerations are the effect of disclosure on the therapeutic relationship, the veteran's trust in the VA medical system, the possibility of discrimination, and the future probability of the veteran's engaging in risky behaviors.
j. Re-disclosure of veteran's HIV antibody status by spouses or sexual partners is discouraged by penalty of law.
k. Documentation in the medical records is essential.

2. **Discussion:**

a. Primary purpose is to protect the health of spouses and sexual partners:

* The Circulars state that there can be no other reason for disclosure of the veteran's positive antibody status. The law apparently does not authorize disclosure to needle-sharing partners, family members, or others not having sexual contact with the veteran. The types of sexual behavior that would have to occur to qualify a third party as a sexual partner are not specified and are therefore open to definition by the veteran and the counselor.

b. Disclosure by health professionals is limited to positive antibody test results:

* Although not addressed, the language suggests that the fact of antibody testing, or negative or indeterminate test results cannot be disclosed. The existence of risky behaviors cannot be disclosed. The information released may be no more than that which is necessary to protect the health of the spouse or sexual partner.

c. Disclosure by health professionals is permitted, not required: Disclosure to protect the health of spouse and sexual partners may not be necessary when:

* Veteran discloses positive test result to spouse or sexual partner. This may occur with or without the counselor's assistance or presence.

* Possible when the health of the spouse/sexual partner is protected by other means. For example when:- the veteran and/or the spouse/partner have not been sexual or have ceased sexual behavior (illness, disability, choice).- the veteran and spouse/partner engage

only in sexual behavior that does not involve the exchange of sexual bodily fluids and is not a recognized risky behavior (mutual masturbation, kissing, etc.)- the veteran and spouse/partner reliably use protective measures such as condoms and dental dams, when engaging in potentially risky sexual behavior. - the veteran and sexual partner have acquired separate living quarters and do not desire further contact

*[See discussion of current vs. former sexual partners below.]

* Or when the spouse or sexual partner cannot be found or "refuses" to appear for face-to-face counseling and disclosure. The policies do not consider situations where spouse/sexual partner is unable to come to medical center if ill, disabled, has no transportation.

* Circular 10-88-151 and 134 note that disclosure can occur only when "necessary to protect the health of the spouse or sexual partner." This statement implies that means other than disclosure may be sufficient to protect their health. However, VHS&RS 151, Suppl 1, seems to remove the option of non-disclosure health protection by other means by limiting the discussion of protection of health only to excluding non-health reasons for notification in Condition 1.a.2. Also Para 1.c. states, "If all the conditions which warrant spouse/sexual partner notification are present, that is, 1.a. through 1.a.3., efforts should be made to conduct notification." The prescriptive clause in Para 1.c. could be interpreted as meaning that non-disclosure means of protecting the health of spouse/sexual partners are not options for counselors. This issue should be clarified with VACO.

d. As the authorization for disclosure of seropositive results to spouse or sexual partner is explained in pre-test counseling and is on the consent form signed by the veteran before HIV antibody testing, there is implied consent for counselor's disclosure of seropositive status under certain conditions specified in the Circulars.

* The language of the consent form implies consent to the release of seropositive test results by the health professional if not disclosed by the veteran. This implied consent does not relieve the counselor from weighing the positive and negative aspects of disclosure. The veteran should also be informed of alternatives to testing and to alternative (anonymous or confidential) testing sites in pre-testing counseling.

e. Disclosure should occur only when necessary to protect the health of the spouse/sexual partner as judged by the health professional, and the counselor has a reasonable belief that the veteran has not voluntarily disclosed, and only after reasonable efforts have been made to counsel and assist the veteran to voluntarily disclose:

* Disclosure by the counselor should occur when efforts to assist the veteran to voluntarily disclose positive antibody status have failed and the spouse/sexual partner's health is apparently at risk. The counselor or health professional has an ethical obligation to understand typical processes of self-disclosure and employ existing therapeutic strategies for assisting seropositive clients in making disclosure decisions.

* Discussing the involvement of the spouse/sexual partner in pre-test counseling and HIV education, before antibody testing, may be a good strategy for some clients. Inclusion of spouse or sexual partner in the counseling/testing process may allow more effective education, facilitate the change of any risky behaviors of both persons, decrease the likelihood of loss of primary relationship if antibody positive, and avoid problems with disclosure (with that partner).

f. The foreseeability of harm to third parties is an important implied concept and involves the judgment that the veteran continues to place spouse/sexual partners at risk.

* It is important to understand that the seropositive veteran is not necessarily a health threat and that the spouse/sexual partner is not necessarily being threatened. These roles may be reversed or not apply. It is important to understand the threat/threatened relationships that may exist before disclosure is considered. The following are examples of factors that might be considered:

* The spouse/partner may face a health risk if no disclosure:- may not know of vet's risky sexual or drug behavior.- may know of sexual or drug behaviors, but not know of HIV risks.- may know of risky behaviors and HIV risks, feel pressured or coerced (may or may not be physical) by vet into unsafe acts, or otherwise be compliant.

* The spouse/sexual partner may not be threatened by the veteran:- may be knowingly engaging in risky sexual or drug behaviors with the vet and/or others.- may already be seropositive (from others)- may be the source of vet's infection (rather than the possible recipient).- may know the risks but deny that it applies to them.

- The veteran's health may actually be threatened by disclosure:- when the veteran is unaware of the risky behavior of the souse/sexual partner, or knows but feels coerced or otherwise compliant.- when the veteran is in a relationship with a physically more powerful partner and when the veteran has previously been physically abused by the partner.- when the veteran is likely to be abandoned by the spouse/sexual partner and left with no shelter, no income, and with responsibility of caring for children and other dependents.

g. Spouses and sexual partners are treated differently with respect to the way in which they are identified:

- Non-spouse sexual partners have to be named by the veteran in the normal course of HIV counseling or antibody testing. However, the activities that constitute normal HIV counseling or antibody testing are not specified. The difference between disclosure and contact tracing is therefore not clear in this instance. What is ethical counselor behavior in these possible examples?- the vet denies the existence of sexual partner in HIV C&T, but in placing your progress note in the medical records you see the name of an apparent sexual partner.- the vet has previously been treated by you and you know of the existence of a primary sexual partner from that treatment. However, a few days (weeks, months) later in the context of HIV C&T, the vet denies the existence of any sexual partner.- the vet identifies two former male or female sexual partners from two months ago, one of whom is pregnant (paternity uncertain).- the vet's most recent identified sexual partner is a male or female prostitute.

- The identification of spouses is not restricted by language in Circulars 151/134 and their identities apparently may be sought from information sources outside of the counseling and testing process.

h. The primary ethical conflict is between protection of health of third parties and the confidentiality of the veteran.

- This is the basic guiding ethical issue. Protection of confidentiality is a central ethical principle in therapeutic, counseling relationships. It is even more important in HIV cases when violations of confidentiality may not only harm the privacy and dignity of the client but may also result in discrimination (housing, health care, insurance, employment, education) against the client. However, there is also an ethical obligation to protect the health of third parties. Violation of confidentiality by disclosure of information believed to be accurate for the purpose of protection of the health of third parties believed to be at risk (spouses or sexual partners in the DVA) has been compelled by statute and upheld by court decisions. The information released may be no more than that which is necessary to protect the health of the third party. The disclosure, if necessary, must be accomplished in a way that protects the confidentiality of the client/veteran as much as possible.

* For the counselor, the recognition of the conflict between confidentiality and disclosure and the knowledgeable consideration of the positive and negative aspects of disclosure for the health of the veteran and spouse/partners in individual situations is the best ethical guide. The documentation of this process in the medical records is the best legal protection.

i. Other important ethical considerations are the effect of disclosure on the therapeutic relationship, the veteran's trust in the VA medical system, the possibility of discrimination, and the future probability of the veteran's engaging in risky behaviors.

* Disclosure by you or by other medical center health professionals may decrease the effectiveness or destroy your therapeutic relationship with the client. This may decrease the health of the veteran in that behavioral and emotional change related to HIV or other diseases (mental or physical) may no longer be possible. Stressful reactions may impair immune function and thereby hasten the progression of symptoms of HIV disease. The veteran may also avoid health care at your medical center, also possibly decreasing the veteran's health and well being. Disclosure of seropositivity to spouse or sexual partner may lead to discrimination and a worsening of life circumstances for the veteran. Finally, the decrease in trust in the therapeutic process, in health professionals, or the demise of a marriage or stable sexual relationship, may actually increase the veteran's engagement in risky sexual or drug behaviors, increasing the risk of infection to unknown others and decreasing the veteran's health because of continued exposure to health risks. Physical abuse of others or self-destructive behavior may also occur. The likelihood of these possible outcomes should be considered and weighed in the decision to disclose positive antibody status.

j. Re-disclosure of veteran's HIV antibody status by spouses or sexual partners is discouraged by penalty of law.

* The health professional must inform the spouse or sexual partner that they may not re-disclose the veteran's positive antibody status to anyone else, under penalty of federal law. Nevertheless, in many situations the likelihood of re-disclosure would be quite high.

k. Documentation in the medical records is essential.

* As mentioned above, documentation of the factors that led to your decision to disclose or not disclose should be entered into the progress notes of the medical records is extremely important. Consultation with an ethics committee or other body might be helpful in considering the relevant factors and arriving at a decision.

Unaddressed Questions:

The Circulars and guidelines do not address these questions:

1. Should disclosure be made to previous and current spouses and sexual partners? Is there an ethical obligation to locate and disclose to all previous sexual partners and spouses named by the veteran during counseling who reasonably might have been exposed to the virus through the veteran?

2. If previous spouses or sexual partners are included in disclosure, how far back in time should one go? Should you disclose to all spouses/sexual partners who had sexual contact with the veteran during and after the estimated time he/she was infected and capable of infecting others? How does one estimate when the veteran was infected?

3. Sexual partners (not spouses) are to be identified by the veteran in association with the HIV counseling or testing process. The information you get often depends on what you ask. Does the veteran have to volunteer that information without prompting? Can you ask for the names of current and previous sexual partners whose health might be at risk) Is there an ethical responsibility to ask for the names of persons who reasonably might be or have been at risk? Is asking for names the protection of health of third parties or is it contact tracing?

4. If it is ethical to ask for names of persons who might now be or who have been at risk, when do you ask? During pre-test counseling? In the first few post-test counseling sessions? Later in the counseling process?

HIV TESTING (SCREENING, NOT DIAGNOSTIC)

ELISA - ENZYME-LINKED IMMUNOSORBENT ASSAY

$10 - $15

COLOR CHANGE

FALSE POSITIVES:
- LAB ERRORS
- CHRONIC LIVER DISEASE
- ALCOHOLIC HEPATITIS
- AUTOIMMUNE DISEASE
- MYELOMA
- PASSIVELY ACQUIRED ANTIBODIES
  - (MOTHER TO INFANT)
  - (IMMUNOGLOBULINS)

WESTERN BLOT - LOOKS FOR SPECIFIC BANDS

LABS DIFFER IN INTERPRETATION OF RESULTS

p24 alone
p24 and p41
p24, p31 and p41 or p60

IFA - IMMUNOFLUORESCENCE ASSAY

SAME PRINCIPLES AS WESTERN BLOT

RECOMBIGEN LA TEST - LATEX AGGLUTINATION

$5 - $10

NO REFRIGERATION NEEDED

5 MINUTES INSTEAD OF 3 HOURS

RECOMMENDED FOR: 3RD WORLD COUNTRIES, EMERGENCY SITUATIONS, ORGAN DONATIONS WHEN LIMITED TIME

MORE FALSE POSITIVES

ANTIGEN CAPTURE ASSAY TEST - MEASURE VIRAL PROTEINS (ANTIGENS)

WINDOW PHASE

VIRAL CULTURES

FOCUS A GUIDE TO AIDS RESEARCH

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New AIDS Prevention Strategies for the I.V. Drug User

Jack B. Stein, LCSW and
Bernard M. Branson, MD

AIDS prevention strategies must be based on principles of health education and must promote risk reduction activities if they are to be effective. Health educators are experienced in promoting behavioral change in a variety of settings and have successfully used a number of strategies. While no one model of intervention offers a "cookbook" solution to the demands of every health-related problem, health educators rely on a theoretical approach, based on previously conducted research, and sometimes "gut feelings" to design new approaches to new problems. Prevention strategies aimed at slowing the spread of HIV infection are often based on previously successful models of behavior change used to promote healthier lifestyles.

A central problem in any behavioral change program is that we all exhibit varying levels of resistance to change. Principles derived from the PRECEDE model of health education (Green, 1980) suggest that to adopt new behaviors we must succeed at the following tasks:

1) recognize that the behavior is truly risky to our health;
2) personalize the risk in such a way that we begin to "own it"; and
3) gain skills for beginning as well as sustaining the required changes.

Risk reduction programs that have incorporated these concepts have been effective in curbing the spread of HIV infection among gay men in the major cities of developed countries. We must learn from these programs and adapt them to meet the challenge of reaching other populations at risk for HIV infection.

High Priority: The I.V. Drug User

Since needle-sharing is one of the primary modes of HIV transmission and thus far constitutes the primary source of heterosexual and pediatric AIDS cases in the United States and other developed countries, health officials must give a high priority to aggressive interventions to discourage needle-sharing among I.V. drug users. Health educators must address these barriers in planning intervention strategies. Some obstacles are inherent characteristics within the I.V. drug use subculture; for example,

1) lack of trust for public health authorities;
2) a position of low regard in society;
3) many language and literacy problems;
4) little sense of community as seen in other populations;
5) activities that have a high likelihood of negative consequences are deeply embedded within subcultural norms and rituals; and
6) a fatalistic acceptance of health risks in general.

These are powerful forces that traditionally thwart health education interventions aimed at I.V. drug users.

Outreach Strategies

The traditional and least controversial strategy for reducing HIV transmission among I.V. users is to discourage continued drug use and to offer treatment, information, and counseling. Statewide drug abuse administrations under the guidance and support of the National Institute on Drug Abuse (NIDA) have developed programs to offer this information to all new and current clients. However, many health educators have argued that these efforts are inadequate given that only 10-20% of all active users are in treatment at any one time. In addition, the number of available drug treatment slots could not accommodate the many individuals who might seek treatment.

> *Recruitment and training of volunteer outreach workers has been encouraged not only to increase the pool of educators but also to use the participatory process itself as a risk reduction strategy.*

The design of a prevention program for I.V. drug users must build upon the knowledge and experience gained during the last few years from other HIV risk reduction efforts. A basic tenet of these programs has been the active participation by the learner, often gay and bisexual men. Evaluations of these programs for gay men, however, have revealed generally higher levels of education, socio-economic status, and sense of community than are frequently found among the I.V. drug-using population. Can such programs be modified to influence risk reduction changes among I.V. drug users not in treatment?

The first step in designing such an outreach program for I.V. drug users is to assess their existing knowledge base. Researchers were surprised to discover the relatively high levels of AIDS awareness and even initial behavior changes already taking place among New York City addicts in treatment as early as 1985. In one such study, 59% of the I.V. drug users interviewed reported having made behavioral changes to reduce their risk of HIV infection, including increased use of new needles, more needle cleaning, and less needle sharing (Friedman, DesJarlais, Sotheran, 1986). Almost 97% of interviewed I.V. drug users in treatment knew that AIDS is transmitted through needle-sharing (Selwyn, 1985). Although not a direct indicator of AIDS awareness and behavior change on the streets, these data confirmed a high interest in prevention information among I.V. drug users.

continued on page 2

THE AIDS HEALTH PROJECT

A Publication of the AIDS Health Project University of California San Francisco

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I.V. Drug User . . .

continued from cover

Over the past two years, several cities in the U.S., Western Europe, and Australia have initiated outreach projects for I.V. drug users. Many of these efforts incorporate active participation of former I.V. users responsible for delivering specific AIDS prevention messages in an accurate, credible, and ongoing fashion. The impact of these projects to date has been extremely promising, but the long-range effects of such interventions will not be felt for some time.

The HERO Outreach Program

In early 1986 the Maryland Drug Abuse Administration provided funding to the Health Education Resource Organization (HERO) to operate in Baltimore a five month pilot project targeted at active I.V. drug abusers not in treatment. (HERO is the primary AIDS prevention organization for the Baltimore metropolitan area). The Street Outreach AIDS Prevention (SOAP) project was designed to reduce the spread of HIV within this population using indigenous, ex-addict community health educators. Due to the uncertain feasibility of such a program in a city like Baltimore, HERO conducted an evaluation of the outreach effort in cooperation with the Harvard School of Public Health under the supervision of William McAuliffe, Ph.D. Program areas under study included recruitment and training methods, the likelihood for drug relapse by workers if they are continually placed in a high-risk environment, the impact of such an intervention on active addicts, and the community's willingness to endorse such efforts.

SOAP selected outreach workers according to specific criteria including knowledge of the streets and drug culture, interpersonal communication skills, length of time in treatment, and the recommendations of treatment counselors. Seven prospective workers attended a two-day orientation and training session conducted by HERO and the state Drug Abuse Administration. Upon completion, four of the seven participants began a four-week "internship" period as SOAP outreach workers to test their education skills on the streets under the close supervision of the project's director.

Each day for one month teams of two or three outreach workers canvassed selected sites. The project director (a social worker with extensive drug treatment experience) and the outreach workers selected target areas known for their high drug use activity. Such sources often relied on inside reports about the frequency, amount, and quality of the drugs available as well as the level of police surveillance. The intent was both to disseminate AIDS prevention information to integrate workers into the neighborhood, thus increasing their level of acceptance and credibility.

SOAP workers used a variety of educational techniques in their outreach efforts. In addition to providing literature and posters to neighborhood businesses and organizations serving the target population, the "ten minute AIDS rap" became the hallmark of the project. On street corners, in store fronts, at bus stops, and in doorways, SOAP workers would approach passers-by with a prepared opening statement about AIDS and engage them in a brief personalized risk assessment and risk reduction lesson. The intervention would then conclude with the distribution of both educational literature and condom samples.

Program Evaluation

SOAP workers interviewed one or two users each day before providing them with any information to determine the level of baseline knowledge on the street. One month later outreach workers conducted follow-up phone interviews with those who offered their names and phone numbers. Eighty-three percent of all individuals were re-interviewed.

The study found that the use of indigenous outreach workers is an extremely operational and cost-effective educational technique. Proper selection, training, and supervision of the workers were noted as the most significant contributions to the success of the project. The pre- and post- surveys of participants' AIDS knowledge indicated significant improvements in awareness. Although measures of behavior change were positive, differences did not prove statistically significant.

Recommendations from the study team included:

1) expanding the program to match better the scope of the drug problem in Baltimore,
2) intensifying the impact of the intervention by increasing the number of visits to an area and offering small bottles of bleach with instructions for cleaning needles,
3) performing periodic serologic testing of addicts to determine better the impact of behavioral changes on seropositivity rates, and
4) expanding the level of community networking performed by the program staff to augment available resources.

Program Administration

At present the SOAP project still operates according to its original model while successfully incorporating some of the recommendations from the evaluation. The project has developed into a comprehensive outreach program with strong community linkages. The program director oversees all administrative management of the program's staff and activities. An outreach team leader (a member of the original outreach worker staff) is responsible for supervising four full-time outreach workers while a case manager assigned to the program responds to requests for social case work and counseling services by the ever-increasing pool of addicts in need of AIDS-related services.

In addition to the monthly street contacts, outreach workers have been invited to conduct educational presentations to clients awaiting intake in a number of drug treatment programs in the area. This has become so popular that weekly scheduled presentations are now provided, allowing AIDS risk awareness to begin early in the treatment process. In addition, outreach to adolescents at risk has begun via regularly scheduled educational presentations and "fun days" sponsored at local community centers that serve this population.

Concerned about the risk of infection and transmission for prostitutes, outreach staff have also conducted several "Women's Health Days" in areas of high activity. Services offered include blood pressure screening, breast examinations, pap smears, anonymous antibody testing and counseling, as well as information and condom distribution. These programs have proven extremely popular and are now scheduled regularly.

Indications of Success

Since the initiation of the special outreach programs in 1986, HERO has learned several lessons about how to intervene effectively with I.V. drug users. These can be summarized as follows:

1) As innovative interventions continue to be developed, professionals must re-evaluate their attitudes regarding addicts' ability to change behaviors in the face of the AIDS epidemic;
2) Similar to the response observed within the gay community, active participation of individuals with I.V. drug use as a risk factor is an important aspect of successful AIDS prevention messages among I.V. drug users. In addition to the extremely positive response by addicts to the outreach workers, the responsibility assumed by the outreach workers themselves has had a profound

impact on their own personal commitment to fighting AIDS. Recruitment and training of volunteer outreach workers has been encouraged not only to increase the pool of educators but also to use the participatory process itself as a risk reduction strategy.

3) Most human service organizations can mount successful outreach efforts to I.V. drug users. Community-based AIDS service organizations are in key positions to conduct outreach efforts to this target population. Preparation is essential. Staff must understand relevant issues related to substance abuse as well as AIDS. They also must take deliberate steps to establish rapport and credibilty within the substance abuse field.

Continued needle-sharing among I.V. drug users poses a critical challenge to health officials and health care workers committed to stopping the spread of HIV infection. The initial success experienced with the SOAP program emphasizes that well-designed strategies beyond traditional approaches merit consideration. An especially important component of the SOAP program has been the ongoing monitoring and evaluation of program methods, orientation, and training. Finally, the effectiveness of the SOAP program indicates that AIDS prevention is possible even among the hard-to-reach population of needle-sharing I.V. drug users.

Jack B. Stein, LCSW *is the Deputy Director of HERO; he is responsible for supervising educational programs including the street outreach project.*
Bernard M. Branson, MD *is the founder and medical director of HERO.*

Diagnosis/Treatment/Prevention

HIV and Homeless Youth

G. Cajetan Luna

The extent of the problem of homeless youth is international and enormous. UNICEF has estimated that more than 40 million youth live in the streets throughout Latin America. The hardships and survival strategies of the gamins of Colombia, the garotos of Brazil, the gypsy children of Europe, the street boys of Egypt, and the gadahis of India, parallel a problem which exists in the United States, where each year more than one and one half million youngsters find themselves in a similar situation.

Economic deprivation has been the major cause for the large number of youth living on the streets of the major cities of the world. Poverty and its social sequelae take a toll on the family unit and are important causal factors which force children out of their families and onto the streets. Many of these youth are loved and wanted, but their families are unable to support them financially. They survive on their own. In addition to poverty, pervasive neglect and physical and sexual abuse are also significant causes.

During the adolescent developmental years, youth explore their sexuality, often including periods of promiscuity and homosexuality. For some unskilled street youth, their bodies may be their only marketable asset. Prostitution is certainly not the only means of survival available to these youth; however, it can provide them with the economic means necessary to remain independent and to provide shelter for themselves. After a life of negative self-image and/or abuse, prostitution can provide an illusion of success for street youth. Many homeless youth drift into street prostitution following the path of least resistance, as they are ill-prepared emotionally, educationally, and vocationally to provide for themselves. Thus, as a result of prostitution, and sometimes needle-sharing I.V. drug use, street youth are at risk for HIV infection.

Although the risk of HIV infection is quite real, the number of reported cases of AIDS in adolescence is small (139 from ages 13 to 19 as of March 30, 1987). Given the long incubation period of HIV infection, theoretically one need only look to those diagnosed with AIDS in their twenties to get a better indication of initial infection among teenagers. The number of cases among those in their twenties is 7029 or approximately 21% of the total.

Three main subpopulations at particularly high risk for HIV infection include (1) street prostitutes — both male and female, hetero and homosexual; (2) refugee youth, and (3) kept youth, or those youth who are supported in part or in full by non-relative adults. This latter group has generally been neglected.

During the past two years the National Institute of Mental Health sponsored in-depth interviews with more than one hundred teenagers on the West Coast who were in the past or are presently being supported by non-relative adults (sometimes referred to as "sugar daddies.") The majority of kept youth interviewed believed their lives were better than in the past, that they were more secure than street prostitutes, and that they were with people who cared for them. Eighty-two of one hundred youth stated they had not had any contact with social service or health care providers since entering the kept relationship. The primary motivation for youth entering these relationships is their need for some semblance of stability in their lives, something that most have never had. However, in most instances, kept relationships eventually result in rejection or further disillusionment.

There is a fear among both service providers and homeless youth that any attention given to this problem will only result in restrictive local or national policy, i.e. surveillance, arrests, and quarantine, at the expense of investments in AIDS-related programs and the necessary measures to improve the homeless situation. Efforts to address this problem must be sensitive to the fact that youth on the streets or in kept relationships are victims. The following related issues will determine which interventions or education programs will prove successful with homeless youth.

First: Societal views about how adolescents should behave sexually are a tangle of contradictions. Given the urgency of instituting proper preventive measures, it is imperative to disentangle moral judgments on sexuality from health care recommendations.

Second: Street youth generally avoid service agencies which could be of potential help. Many fear agencies might contact parents, returning them to an abusive environment or sending them to youth institutions believed to be harsher or more unjust than the streets. In order to address the risk of HIV infection among this population, simultaneous efforts must be made to create more programs for independent living, offer vocational training and job opportunities, provide educational services, and most importantly provide extended housing.

Given the transient nature of homeless youth, any education program which is not embedded in the information flow of the street will prove ineffectual.

If they are to be successful, AIDS prevention programs must reach the population at highest risk developmentally; namely adolescents, since behavioral patterns incorporated during this period are often carried into later life. Those individuals vulnerable to exploitation and abuse among the world's adolescent street populations must be targeted by public health intervention programs specifically.

G. Cajetan Luna *is a medical anthropologist in the Department of Epidemiology and International Health at the University of California, San Francisco School of Medicine.*

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MILD AND SEVERE SYMPTOMS OF ADDICTION

MILD	SEVERE
Absenteeism, tardiness	A.W.O.L.
Uneven performance	Severe drop in performance
Minor accidents	Serious accidents
Intoxication off-duty	Intoxication on the job
Concern from co-workers	Pathology in co-workers

Family/Significant Other(s)

Loss of communication/affection	Separation/divorce
Arguments	Violence
Concern of codependents	Pathology of codependents
Family history of addiction	Extensive family history of addiction

Health/Physical Well-Being/Nutrition

Increasing tolerance	Decreasing tolerance
Minor physical complaints	gastritis, pancreatitis,
System rebond reaction	cancer, cirrhosis,
Minor nutritional deficiency	heart disease, etc.withdrawal symptoms
	serious deficiency

Emotional Stability/Strength/Wellness

Minor problems--mood changes	Wild fluctuation
Memory lapses/blackouts	Serious memory deficiency
Occasional dysfunction	Recurring dysfunction

Social Relationships/Friendships/Social Standing

Change in friendships	Social circle limited to
Withdrawal of involvement	users, isolation
Telephonitis/deterioration	Loss of friends

Behaviors/Hobbies/Interests/Recreation

Declining interest, involvement	No interest
Positive or neutral for self-esteem	Negative for self-esteem
Difficulty in coping	Self-defeating

best copy available

Legal/Financial Stability

Debts	Bankruptcy/indigency
Occasional, minor legal problems	Criminal charges

Bella H. Selan

HEALTH RISKS
Transmitting Disease by Sharing Needles

AIDS, hepatitis-B and endocarditis are the most serious disease risks.

AIDS

AIDS stands for Acquired Immune Deficiency Syndrome. It is a life-threatening disease that damages the ability of the blood in healthy people to wipe out invading germs, viruses or other infections.

Symptoms

* Unexplained increasing and persistent fatigue;
* Persistent fever, 101-102, and night sweats unexplained for several weeks;
* Swollen lymph nodes, in addition to those in the groin area swollen from sexually-transmitted diseases;
* Creamy-white patches on the tongue and/or mouth;
* Pink or purple flat or raised blotches that don't go away and do not pale when pressed;
* Diarrhea or bloody stools;
* Dry cough

The above symptoms can appear with other diseases which may not be AIDS. However, if these symptoms or combination of symptoms appear, seek medical help immediately.

HEPATITIS-B

Hepatitis-B is a viral infection of the liver.

Symptoms

* General weakness;
* Abdominal pain;
* Nausea;
* Appetite loss;
* Jaundice (yellow eyes or skin);
* Tea-colored urine;
* Light-colored stools.

ENDOCARDITIS

Endocarditis is an infection of the heart, usually caused by bacteria rather than by viruses.

Symptoms

* Fever;
* Chest pain;
* Shortness of breath;

- Fainting spells.

DRUG OVERDOSE

every injection of "street" drugs has a risk of a sudden bad reaction, because you do not know how much of the drug you are taking, the amount of impurities, or the "allergic reaction" of the user.

EMBOLISM

If particles or air bubbles are injected, they can become lodged and block blood flow.

ABSCESSES

These are local bacterial infections at the injection site.

TETANUS

This disease caused by bacterial infection can result from skin-popping drugs.

REDUCING YOUR RISK

There are always health risks associated with the any use of drugs by injection. The only way to avoid these risks is not to use needles. If you continue to inject drugs, the following measures will reduce your risk:

Don't share needles!

Sharing needles can share disease, too. Obtain your own "works" and don't let anyone else use them.

Clean your works

Wash needle and syringe with bleach or alcohol after each use, then leave them to soak in alcohol until the next use.

Clean your skin

With alcohol, before injecting.

Keep healthy

If you are in a weakened state, you are more likely to get a disease. Eat a balanced diet, get enough rest and exercise, and get medical care when you need it.

FACTS ABOUT IV DRUG ABUSERS WHICH AFFECT AIDS COUNSELING

1. Unlike gay persons, IV drug abusers do not have a tightly knit, extensive support system.

2. They are not part of society and are viewed as "deadbeats on welfare" who contribute nothing worthwhile to society.

3. Drug abusers who are middle class or upper class are rarely conceptualized in the same way as the lower class drug abuser is. Upper and middle class drug abusers are either identified as "having a problem" or as "impaired physicians, impaired lawyers", and help is available to them through an extensive network of private services, insurance companies, and friends as well as peers.

4. The 11% of gay persons who are also IV drug abusers in most cases still qualify for the extensive support the gay community offers its members.

5. Long-time IV drug abusers view their drug abuse problems as a sign of society's lack of care for them, as a government plot and often blame the very agencies or counselors who are trying to help them.

6. IV drug abusers basically have a very, very low self-esteem which they cover with what Freud called the "idealized self". They have very ego-dystonic ideas about themselves; bragging on the one hand how they have survived on the streets because they are "smart" and know how to survive even overdoses, and knowing on the other hand that they have little control over their lives and destinies.

7. Many of the IV drug users have alienated their own families to such a degree that they do not ever want to hear from them again, and are not likely to.

8. Many IV drug users quite casually do things which are against the law to support a habit. A $100-a-day habit requires approximately $400-$500 of stolen goods. A prostitute has to turn 10-20 tricks a day to support her habit and pay off her pimp and various other persons for protection.

9. IV drug abusers profess to have, and perhaps do have, deep concerns for their children, but often are neglectful or abusing parents, since this is a pattern they themselves have been subjected to.

10. Unless IV drug abusers are seriously into recovery, most of them spend almost all of their time thinking about getting the next fix.

11. Many IV drug abusers have been incarcerated at least once.

12. Contrary to popular opinion, most IV drug abusers have excellent survivor skills and do not want to expose themselves to the AIDS virus.

13. Despite the popular notion that drug abusers are not willing to change anything, Dr. Don Des Jarlais of New York City has found that 59% of 659 drug users he surveyed were willing to change needle sharing behavior after learning about its connection to AIDS.

14. The addict who is in treatment toward recovery is the one accessible to counseling and risk reduction work - the active street abuser will probably not be seen in your offices.

Bella H. Selan

POSSIBLE MESSAGE FOR AIDS HEALTH COMMUNICATIONS BY TARGET AUDIENCES

IV DRUG USERS

1. Stop using drugs, seek treatment.
2. If use is continued, don't share contaminated needles.

IV DRUG USER - RECOVERING

1. Seek HIV testing. If practiced needle sharing in past.
2. Remain drug free.3. Use condoms.

IV DRUG USER - RESISTANT TO COUNSELING AND TREATMENT

1. Use needle hygiene recommendations if needles (or works) are shared.
2. Never share needles with person suspected of being HIV infected.
3. Use condoms.

FEMALE IV DRUG USER

1. Consider counseling on AIDS and pregnancy.
2. Avoid pregnancy if needle sharing ever practiced.
3. Refrain from oral/anal intercourse with persons suspected of being HIV positive.
4. Postpone conception if HIV positive.

YOUTH APPROACHING AGE WHEN SEXUAL AND DRUG EXPERIMENTATION MAY OCCUR

1. Know safer sex practices, if not sexually active.
2. Avoid use of drugs, especially drugs used intravenously.
3. Practice safer sex guidelines, if sexually active.

SEXUALLY ACTIVE ADULTS

1. Have fewer partners.
2. Screen partners on past sexual and drug-using practices.
3. Practice safer sex guidelines.

GENERAL POPULATION

1. Promote awareness of effective ways to control HIV transmission.
2. Promote and support coalition activities on AIDS and IV drug use.
3. Begin (or continue) to support drug abuse prevention activities, especially targeted toward youth.

Comments on Currents

Providing Empowerment to the Person with AIDS

Patrick Haney

I hope to put a face to the dry statistics, so often encountered regarding acquired immune deficiency syndrome (AIDS) by sharing my experiences as a person with AIDS. I want to start from my diagnosis with AIDS-related complex (ARC) and proceed through my recent diagnosis with AIDS—a period of more than three years. Also, I hope to provide some tools and resources social workers can implement when assisting a person with AIDS.

The Brick Wall

My diagnosis with ARC was lengthy, frustrating, and expensive. It took several months, three physicians, and hundreds of dollars in testing. That was in June 1984. I knew what the doctors suspected, and I thought I was prepared for the diagnosis, because it took so long. I wasn't. Hearing the diagnosis, I ran into a brick wall. I thought I'd be dead by the end of the week.

Psychological support at the time of diagnosis (whether of AIDS, ARC, or exposure to human immunodeficiency virus [HIV]) is crucial to preventing fear and anger from being transformed into self-destruction. For the person being diagnosed with ARC to become fearful and want to flee from the syndrome is the most natural reaction I can think of. AIDS has become closely associated with horrifyingly negative pictures of incapacitation, abandonment, rejection, hatred, physical and mental deterioration, and deformity. When one is faced with these bleak and barren prospects associated with AIDS, suicide becomes a viable alternative. Providing support at the time of diagnosis, as well as afterward, is tremendously important. Remember that sometimes it takes a while for the news of being HIV infected to sink in.

My diagnosis of having AIDS was another brick wall. This time it was a brick wall of denial. For two months I coped by believing everything was fine, no problem. But lately, my very real fears, my sense of loss and disappointment, and my sadness have affected me powerfully. And I'm working through my feelings with a lot of concern and support from my therapist, support groups, friends, and family. I believe I'm finally making real progress toward acceptance of my having AIDS.

Crystal-Ball Predictions

There are two statements many physicians communicate to persons with AIDS that are counterproductive, frustrating, and unnecessary: (1) There's nothing we can do; and (2) You have *x* months to live. Incredible frustration accompanies any pronouncement about there being nothing anyone can do. That statement does nothing other than foster in the person with AIDS a sense of utter despair and hopelessness. Moreover, it is defeatist and fatalistic, undermining any reason for the person with AIDS to fight back. This kind of thinking adds fuel to the fire of panic and fear that usually accompanies knowledge of HIV infection. It has no place in a constructive approach—helping the persons with AIDS to cope.

Predictions about how long the person with AIDS has to live is simply a game of statistics and fortune-telling. Doesn't it make more sense to help the person with AIDS to focus on the possibilities of living with AIDS rather than on a negative self-fulfilling prophecy? Sure, most persons with AIDS may die within two years of diagnosis. But not all of us do. There is nothing constructive in setting up the person with AIDS to believe he or she will be dead within *x* number of months, no matter how "statistically correct" this prognosis might be.

Life after Diagnosis: The Negatives

For many persons with AIDS, there was one life before diagnosis and another life after diagnosis (life A.D.). For some it's a giving in and a giving up; for others it's the beginning of a whole new way of thinking and being. I have always believed all situations have positive and negative aspects. I used to tell my clients to look for the positive in what appeared to be totally negative situations. Now I'm having the opportunity to follow my own advice.

For me, life A.D. has had both positive and negative aspects. Of the more negative aspects, those things that stand out the most have been the "them and us" mentality, disconnections, shame and blame, the need to hide, and the potential to focus exclusively on the negative. The "them and us" mentality is a way of thinking about AIDS that encourages people to think it's not a problem *they* need to worry about, because AIDS primarily affects *them*. Most of us know who "them" are: gay men, drug abusers, hemophiliacs, Haitians, blacks, Hispanics, women, prostitutes, and some children. Also, the way AIDS is reported, with high-risk groups, lends itself to further isolation and disconnection from those of us who are sick. It is as if we are some fringe element "out there," an element unworthy of compassion because of some character flaw or inappropriate behavior.

I see many of the potential psychosocial consequences of AIDS as disconnections: disconnections from our past, present, and future; from our loved ones; from ways we have of defining ourselves, such as job activities, capabilities, skills, and physical appearance. Finally, AIDS may lead to disconnection from things many of us take for granted, such as a sense of power and control over our lives, hopes, dreams, and aspirations. This further exacerbates the sense of isolation, alienation, and aloneness that persons with AIDS experience.

Another negative aspect of AIDS that I have experienced is the shame and blame that accompanies the disease. Like no other illness since the advent of modern medicine, AIDS carries with it a stigma of shame and pointed finger of blame, suggesting those of us who are sick are at fault for being infected. This is a very negative impact of AIDS, yet it is also illogical. Do we blame Legionnaires for Legionnaires' disease; children for mumps, measles, or chicken pox; the elderly for Alzheimer's disease or death; or epileptics for seizures? It makes no sense to blame anyone for AIDS. AIDS is caused by a virus, not by behavior or identity.

Moreover, shame and blame can lead persons with AIDS into denial and hiding, which may cause potential avoidance of medical care, involvement in unsafe sexual activity, and a lack of support from a support system that doesn't know the person is HIV infected. This further isolates the person with AIDS and exacerbates feelings of aloneness and despair, and threatens the health and welfare of the person with AIDS. The stigma of AIDS even leads some physicians deliberately to misdiagnose patients, sometimes putting a different cause of death on a patient's death

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certificate, or otherwise to underreport the occurrence of HIV infection.

Finally, I have found I need to be careful not to focus on the negative aspects of my experience, which can be overwhelming. My energies are better utilized when I focus more on solutions than on problems. Finding gratitude for what I *do* have is very difficult at times. Yet focusing on gratitude may be the only lifeline I have.

Providing Empowerment

The bottom line in helping persons with AIDS is to assist us in focusing on learning to live with AIDS. One person with AIDS put it this way:

> I will share a little secret of my survival with you. Having people give unselfishly of themselves, that enables us to feel loved, supported, wanted. These powerful feelings can help [persons with AIDS] reach the understanding that we are not helpless, that we can help ourselves, that we can heal ourselves. We must have a say in our therapies. The assertion that we do not have to die from AIDS is very, very important. We have the ability to extend our lives and to enrich the quality of our lives. But this is difficult to do alone. I need help to focus on living with AIDS, not dying with dignity.[1]

There are many ways of providing empowerment to persons with AIDS. I will share with you six ways that have benefited me the most. However, this is not intended to be an exhaustive list. Also, keep in mind that persons with AIDS are a remarkable resource in helping others who have AIDS.

Focus on the Positive, Less Fatalistic Aspects of Having AIDS. The social worker needs to help persons with AIDS focus on the positive aspects of their experience. This is not accomplished by denying that what is happening because of AIDS is bad. Rather, it can be accomplished by helping persons with AIDS realize that positive can come from any negative experience. Persons with AIDS need to be shown how to make the most of an otherwise bad situation. Present to persons with AIDS the exceptions to the rules; provide an alternative to the medical community's negative predictions that persons with AIDS survive only 18 months or so. There are persons with AIDS who live longer than two years after diagnosis. Maybe there aren't many, but there are some. If one persons can survive, so can another. I wonder how much shorter some lives of persons with AIDS have been because of negative, self-fulfilling prophecies? Some of the positive consequences I have experienced since my HIV infection include learning to accept my limitations; learning to cope by getting in touch with my strengths, experiencing a clarity of purpose; learning to live one day at a time; learning to focus on the good in my life here and now; and the incredibly moving experience of having complete support and love from my family, friends, lover, people I hardly know, and sometimes even complete strangers.

The Healing Power of Hope and Caring. We understand very little scientifically about the power of hope and caring. However, it is clear how vital they are to our survival. Social workers must assist the person with AIDS to find hope and caring. If the person with AIDS has no friends or family who are supportive, social workers must help them find people who will care for them and support them. Social workers themselves must provide that caring and support.

Reconnections. AIDS is truly devastating in its effect of disconnecting the person with AIDS from things that have a lot of meaning. For example, many persons with AIDS become unable to work. This has the potential of destroying a sense of productivity and contribution and disconnecting the person with AIDS from a sense of self-worth. Furthermore, this disconnects the person with AIDS from a sense of future, something to work toward and look forward to. Persons with AIDS need assistance to realize a sense of purpose and meaning, whether through job rehabilitation, assistance redefining self-worth, or help finding a flexible job so the person with AIDS can work when feeling energetic.

Perhaps the most fundamental area that persons with AIDS need reconnecting with is a support system. Often persons with AIDS find themselves abandoned by family, friends, spouse, children, or lovers. If ever there is a time when the support of friends and family is needed, it is during and following the crisis of being diagnosed with AIDS and trying to live with AIDS.

One incredibly potent support system, which often is underutilized, is the support group. The hope and strength we get from each other in a support group has made support groups a vital part of my own coping with AIDS. It was through attending my first support group that I found the beginning of hope. Following my diagnosis with ARC, I had succumbed to a "death is inevitable" mindset. It took direct contact with other persons with AIDS to begin to shake me loose from this mindset. Attending the group for the first time was not easy. It is difficult to deny that you are ill with AIDS once you start attending an AIDS support group.

I overrode my fears, and I'm thankful I did. I met two other persons with AIDS who had been living with their illness for almost three years. These two men were joking laughing, and having a good time. Here were two men with a supposedly fatal disease acting as if nothing were wrong. They were acting like a couple of well people, which really eroded the negative mindset I had. It was the beginning of my learning to cope. An important aspect of this experience was my vital need to connect with others who had gone through a similar experience and had learned to live with it. I found a place where I felt I belonged.

A final thought about reconnections: When I was diagnosed with ARC, my father insisted on speaking with my doctor. He told my doctor that he and my stepmother would do whatever was needed to ensure that I would get the best possible medical treatment. If necessary, he said, they would sell their home to finance my care. I am fortunate. My family and friends have been there for me over and over again. I don't think I would be alive today if they had not been there.

Power, Control, and Direction. One of the most crippling aspects of AIDS is the loss of power and control over life that the infected person experiences. Loss of power and control may extend to many areas, but especially affects how the persons with AIDS deals with AIDS. Social workers can provide persons with AIDS with ways to control thei illness and their lives. Some of these include massage therapy, acupuncture, holistic medicine, meditation, creative visualizations, affirmations, nutrition, emotional support, coping skills training, anxiety and stress reduction, relaxation exercises, individual counseling, group therapy and support groups, and experimental drug treatments. Furthermore, persons with AIDS can be helped ridding themselves of negative feelings, learning to forgive, and learning to love themselves. Power and control over their lives give persons with AIDS hope and direction, and provide keys to not giving up. A sense of power and control is an integral part of providing empowerment to persons with AIDS.

Victim Mindset. I never refer to myself or others as "AIDS victims," but rather as a "person with AIDS." This is not a game of semantics. As another person with AIDS related

> Not buying into the victim mindset is keeping me alive. To me 'victim' implies helplessness and passivity. At this time in my illness, I am not helpless and I am anything but passive in dealing with it. I can look around and I see incredibly courageous men who inspire me with their strength. These men continue t

> defy the odds and say no to AIDS. They give me hope. They give me strength.[2]

The beginning of helping persons with AIDS not to view themselves as victims is not buying into the notion yourself.

> To label us as 'victims'...implies defeat, and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence upon the care of others. We are 'people with AIDS.' "[3]

Advocacy. As important as it is that persons with AIDS be allowed to do what they can for themselves, it is equally important they be helped when they need to be. It is empowering, reassuring, and truly beneficial to know help is there when it's needed. Advocate for our needs and our rights.

Social work has traditionally supported and advocated for the disenfranchised groups in our country—black people, Hispanics, children, the poor, women, and gays. Moreover, social work values have included belief in all people's worth and dignity, belief in the individual's capacity for growth and self-determination, acceptance of the uniqueness of the individual, and the importance of self-help and client participation.

AIDS affects us all, whether directly or indirectly. We who are infected are your sons and daughters, brothers and sisters, mothers and fathers, neighbors, co-workers, fellow students, and friends. Each and every one of us are members of one race—the human race. We must all become responsible, individually and collectively, for striking out against the numerous injustices connected with AIDS. Let us send ripples of hope to persons with HIV infection and begin to break down the walls of fear, oppression, and ignorance.

Notes and References

1. Anonymous person with AIDS, personal conversation.
2. Anonymous person with AIDS, personal conversation.
3. Advisory Committee of People with AIDS, statement made during National Lesbian/Gay Health Conference, Denver, Colo., June 1983.

Patrick Haney founded the first AIDS information and referral service in Palm Beach County, Florida, in 1984. Later, he established the Persons with AIDS Coalition, a support network. Following his death on February 6, 1988, the Florida Chapter of NASW honored him with a Special Recognition Award for his work in AIDS education. Palm Beach County has named its 30-bed Special Care Facility for Haney.

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TEST YOURSELF

Answer the following questions to find out whether you need malpractice coverage.

Y N
1. ☐ ☐ I am a practicing social worker.
2. ☐ ☐ I don't have my own coverage if I'm sued for malpractice.
3. ☐ ☐ I let my malpractice coverage drop.
4. ☐ ☐ I've heard about other social workers being sued.
5. ☐ ☐ I know I need my own liability insurance, even though my employer provides it.
6. ☐ ☐ I'm aware that malpractice suits against social workers have considerably increased over the past few years.
7. ☐ ☐ I don't want to worry about being sued.

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Comments on Currents

Risks of Abstinence: Sexual Decision Making in the AIDS Era

Harvey L. Gochros

Rarely have social workers been called upon so suddenly to deal with problems as massive, complex, and urgent as those associated with human immunodeficiency virus (HIV) infections. It is likely that our involvement with this disease has just begin. Acquired immune deficiency syndrome (AIDS) seems to have emerged overnight, but despite fervent hopes, AIDS will not go away suddenly. There may be neither a vaccine nor a cure for the disease in this century. The social and emotional problems associated with HIV infections will become more urgent and complex as the number of people who have AIDS increases, their life expectancies grow, and the range of physical, social, and psychological sequelae of the disease expand.

Recent projections suggest that by 1991 the number of people who have HIV-associated physical and emotional diseases will increase at least fivefold, and that by the beginning of the next decade more than 50,000 Americans will die from AIDS-related causes each year.[1] Indeed, Mahler, head of the World Health Organization, stated that he

> could not imagine a worse health problem in this century....We stand nakedly in front of a very serious pandemic as mortal as any pandemic there has even been. I don't know of any killer greater than AIDS, not to speak of its psychological, social and economic maiming.[2]

Throughout the nation—and especially in the largest cities—social workers have responded to the AIDS epidemic responsibly and quickly. However, we have only begun, as a profession, to ask some of the crucial questions that ultimately must be answered.

Certainly social work's first priority will continue to be to act as advocates and brokers for those who have HIV infections. We also must offer sensitive counseling, from diagnosis to death, to people infected with the HIV virus, and to their lovers and other family members.

A second challenge is to guarantee that the civil rights of those with HIV infections are preserved in such areas as employment, housing, and privacy; confidentiality and informed consent also are essential to HIV testing programs. Social workers must work to forestall incipient societal paranoia, scapegoating, and destructive public policies that often characterize national responses to major public crises. Those most at risk for the disease will continue to be members of socially unloved groups—racial and ethnic minorities, drug abusers, and gay men—who could be the targets of a frightened public seeking simple solutions and scapegoats for a perplexing national crisis.

In addition to these tasks, social workers will increasingly be called on to help reduce the spread of the disease by educating and counseling people who engage in the high-risk behaviors most directly linked to the spread of AIDS: certain sexual acts and sharing hypodermic needles. Although there are signs that the incidence of HIV infections resulting from sexual activities is beginning to level off,[3] the rate of transmission through shared needles continues to rise at a frightening pace. Efforts to control this method of HIV transmission are complex and are beyond the scope of this article. This article will explore efforts to reduce the sexual transmission of AIDS, and specifically will respond to those who urge sexual abstinence as the primary solution to the AIDS crisis.

Myths of Abstinence

The majority of HIV infections in the United States today were sexually transmitted. For physiological reasons, this transmission is most likely to occur through vaginal or anal intercourse; the latter has higher probability of transmission. A simplistic solution offered by many is that those at risk should abstain from sex. Indeed, a recent Department of Education guide for parents and teachers of adolescents advocated abstinence as the only solution to AIDS.[4]

Those who recommend this solution correctly point out that complete abstinence is the only certain way to avoid infection. Not so correct is an alternate solution some offer: entering and/or maintaining a monogamous sexual relationship. Unless testing has established that both partners have not been exposed to HIV, there is no more a guarantee that a monogamous relationship is virus free than a one-night stand. It is therefore true that most sexual relationships introduce some degree of risk. But abstinence also brings with it varying degrees of risk that must be considered in social work educational and counseling efforts with people attempting to make crucial sexual decisions.

The AIDS epidemic has brought forth an avalanche of dogmatic traditional morality cloaked in public health terms so that even the surgeon general has had to justify offering alternative to abstinence. Indeed, sexual practices that conform to "safer sex" guidelines often are presented as second best. Such approaches begrudgingly accept sex in the belief that people just can not be stopped from having sex no matter how much we would like to stop them.

Social work values suggest that we must accept—and support—pluralistic bases for choices people make about their sexual lives, recognizing some possible risks, rather than working dogmatically toward a universal acceptance of abstinence. Furthermore, we must recognize that abstinence itself poses some risks.

Social workers' clients often seek guidance from them about complex personal decisions. There are other situations in which social workers observe client attitudes, beliefs, or behaviors that they perceive to be potentially hazardous to their clients' well-being. To offer effective help for clients in making difficult sexual decisions, social workers should consider a number of questions concerning the risks of sex and abstinence.

Meanings of Abstinence

Discussions of abstinence are difficult because it is not clear exactly what abstinence is. Sexuality and sexual expression take many forms; which behaviors specifically qualify as abstinence? There is a wide spectrum of behaviors and potential risks between hand holding and unprotected anal intercourse. Few would argue against advocating avoidance of unprotected high-risk sexual behaviors. However, some advocates for abstinence argue against any activity that could lead to sexual arousal. If abstinence is to be considered seriously as a solution for AIDS, it should be clear what we are asking people to abstain from and why.

Spectrum of Behaviors

It is a naive but common belief that the only sexual options are shaking hands or having intercourse. In the words of one client,

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"a man never starts something he can't finish!"

The human body and the human imagination are capable of a myriad intimate sexual options between these two extremes. A majority of these contacts have minimal or no probability of transmitting HIV.

The belief that there is only one logical vehicle for sexual expression, going "all the way," must be overcome. High teenage pregnancy rates attest to the hazards of such a belief. Sound AIDS education must begin with comprehensive sex education that teaches the range of sexual expression and that the acts of physical intimacy need not be hazardous.

Just Say, "No"

When pressed, the advocates of the "just say no" solution to AIDS recognize that something must be offered to fill the void abstinence leaves. Their recommendations sound unrealistic at best and reflect the barely covert fundamentalist moral foundation of their appraoch. For example, a state senator who opposed safe sex education in Hawaii public schools suggested that schools should teach students abstinence and

> ...that the key to controlling their sexual energy is redirecting it to non-sexual physical activities, such as competitive or recreational sports, yoga, or martial arts, mental activities, such as study, art or music; social activities such as working with church groups, senior citizens or volunteer work; or spiritual activities, such as the study of scripture, prayer, meditation or devotional services.[5]

He offered no evidence that such sublimations work.

Reiss suggested that vows of celibacy have a far higher breakage rate than condoms.[6] If efforts to control sexual urges by spiritual and other measures were successful, there would not be so many priests contracting AIDS. There is little evidence that sexual urges can successfully be sublimated by most people through nonsexual activities. The desire for sexual release, the need for affectionate tactile contact, and for sexual union are universal and powerful.

Functions of Sex

Diverse sexual activities serve many social and psychological functions in human beings in addition to reproduction and pleasantly quieting erotic urges; they express and confirm a sense of maleness and femaleness.[7] They celebrate life and often overcome, at least temporarily, feelings of loneliness. Sex, in its various forms, can perhaps most significantly be a vehicle for communicating love, intimacy, and union with important people in one's life.

Most people prefer to and are able to meet these needs through more or less satisfying, long-term monogamous relationships. Not everyone, however, is capable of long-term relationships, and there are others who do not want them. For a number of reasons many prefer short-term relationships.[8] These people are not incapable of or not desirous of love. Love comes in many forms, and there is no evidence that long-term relationships guarantee happiness and true intimacy anymore than do briefer ones. In Chesley's play *Jerker*, one character protests that love between strangers often is "still love, even if only for a few hours, and a virus can't change that fact."[9]

Sex is connected intimately with love. Fears of AIDS must not obscure that fact. Those who consider the option of abstinence must be sensitive to the symbolism of physical union as expressions of love. If all forms of making love are made to appear bad and dangerous, are the expression and development of love inhibited? To do so would surely have harmful effects on individuals and society as a whole.

Risk of Infection

Unfortunately, in the eagerness to stop AIDS, some have confused some important factors in the HIV equation. For example, promiscuity is frequently linked with AIDS risk. It is not, however, how many sexual encounters one has but the nature of the sexual activities that determine the risk levels of sexual choices. For example, a recent study of a large cohort of prostitutes who used condoms and did not share hypodermic needles found extremely low levels of HIV infection.[9]

Carried to an extreme, one might engage in body rubbing, hugging, kissing, and mutual masturbation with dozens of partners and not risk infection, while unprotected anal sex once with only one partner could lead to infection. Once again, the universal myth that sex does, must, or should ultimately involve a penis in an orifice leads some to generalize the hazards of such activities to the hazards of all forms of sexual expression. Risk of AIDS contagion does not necessarily depend on the numbers of sexual partners one has in a lifetime, but on the sexual behaviors in which one engages.

The following crude example may be useful to predict a person's risk of HIV exposure:

> Number of partners × Probability partner(s) is (are) infected × Risk of particular sexual acts = Probability individual will become infected

As any one of the three variables in the equation approaches zero, the probability that the individual will become infected diminishes significantly.

Consequences of Abstinence

Although many people are reducing the number of casual sexual encounters they have, and are engaging in safer sex practices,[11] there is little evidence that large numbers of people are choosing complete abstinence. Abstinence on a large scale also may cause other social problems. For example, sexual repression may be linked to aggression, as studies of sexual deprivation of prisoners and prison violence have shown.[12] Sexually repressive societies also may be likely to be warlike.[13] Albert Einstein wrote to Sigmund Freud in 1932 to ask what could be done to avoid war. Freud replied that human instincts are of only two kinds: (1) those that seek to preserve and unite (Eros), and (2) those that seek to destroy (Thanatos). Among humans, Freud suggested, the forces of love and the forces of hate are always in a delicate balance. Freud believed that humanity's destructive potential always exists, right below the surface, held in check only by the balancing effect of Eros. Efforts to expand and perpetuate the practice of abstinence could tip that balance individually and collectively.

Such speculation is fortified by the works of social psychologists who subscribe to Dollard et al.'s hypotheses that frustration always leads to some form of aggression and aggression always is a consequence of frustration.[14] They further observed that frustration is especially intense when people's motivation to achieve a goal is strong, blocking of the goal is complete, and frustrating experiences are repeated. When these conditions occur, it is likely that aggression will build until it is released in one form or another. These conditions for aggression are met when those for whom sexual expression is important practice abstinence.

The long-term consequences of sexual abstinence on individuals or on society as a whole are not known. Attempting to inhibit sexual desires may contribute to an increase in alcohol and drug abuse.[15] Ironically, these behaviors ultimately could lead to a reduction of judgment and impulse control and to consequent hazardous sexual behaviors. Indeed, there is another possible danger for those individuals who attempt to comply with the recommendation of abstinence: they may engage impulsively in dangerous sexual activities they would never have done had they moderated their sexual desires and activities.

Attitudes about Sex

American society increasingly has become uncomfortable about sex since the sexual experimentation and freedom that disappointed many in the 1960s and 1970s. In recent years the media and sexual education programs have focused on the negative aspects of sex. Such forms of sexual exploitation as rape, incest, child sex abuse, sexual harassment, and degrading and violent pornography make the headlines and the course content of human behavior classes. The AIDS epidemic has added enormously to the American ambivalence about sex. Americans are preoccupied with sex, as reflected in films and television programs and at the same time highly moralistic about it as reflected in the investigations and revelations leading to the downfall of national political candidates and television evangelists.

The implicit condemnation of many common forms of sexual expression in "just say no" campaigns adds to the powerful tension people experience. People should learn to accept sex more calmly. By emphasizing the dangers of sex and ignoring the fact that most responsible sexual acts by most responsible people do not lead to pregnancy, disease, or death, the healthy, joyful, naturalness of sexuality is obscured.

Sex and Risk

The risk of death from sexual activities can be compared with the risk of fatal car accidents. The risks of both can be reduced greatly by deliberate responsible behavior without sacrificing pleasures and needs. Despite efforts, however, driving and sex will continue to involve risks. Yet the solution to fatal traffic accidents is not to urge all people to stop driving. And although young people are more at risk for fatal traffic accidents and, indeed put the rest of society at greater risk, we do not withhold car keys from young people until they are statistically safe adults. Society recognizes that driving is necessary to most people and that with responsibility, it can be enjoyed relatively safely. We therefore try to teach people how to drive as safely as possible, how to minimize their—and other drivers'—risks, and enforce traffic laws based on knowledge of safer driving. The same strategy can work in addressing the risks of sex.

Most people cannot, need not, and should not say "no" to sex. The author observes that most advocates of total abstinence are in their senior years with relatively few years of sexual activity ahead of them while they address young people who have half a century of potential sexual desires and opportunities ahead of them.

People are modifying (but not giving up) sexual activities in response to the AIDS epidemic. A Gallup poll found that 55 percent of those interviewed were taking steps to avoid contact with the virus, including using condoms and choosing sexual partners more carefully.[16] The incidence of such sexually transmitted diseases as anal gonorrhea recently has been dramatically reduced, as have the rates of new HIV infections among the gay male communities in major American cities.[17] These reports suggest that people need not give up sex to reduce the risk of HIV infection. Rather they must adjust their sexual behaviors.

Mandate for Social Workers

One sexual standard cannot be adopted for all people. Sexual expression is a powerful and personal part of most people's lives. Each person must think through his or her own responsible sexual choices. Social workers can help this process by sharing the facts of HIV infection with those people for whom they care. We also must work for a social climate in which people can reach their decisions in a calm, thoughtful, sex-affirming atmosphere. We must fight the value that impulsive sex is acceptable but that planned, thoughtful, open sexual encounters—premeditated sex—is bad. A culture that considers spontaneous sexual activites understandable and forgivable, but considers that planned sexual encounters are bad, invites not only AIDS but also high abortion and teenage pregnancy rates.

Social workers cannot support the thesis that the only alternatives to abstinence are amorality, permissiveness, and sure death. We must deal with a cultural history in which condoms were seen as a symbol of immoral, clandestine, casual, and dirty sex. We must assert that sexual desire, planned sexual encounters, sexual talk between actual or potential sexual partners, and condoms are good common sense.

The AIDS crisis forces social workers and clients alike to face up to who we are and what we want as sexual human beings. Just as there is no vaccine or cure for AIDS, there is no universal risk-free strategy for its prevention. Sex can be risky, abstinence can be risky, living is risky.

We cannot avoid risk if we want to live. This certainly does not give us license to risk the lives of other people. The rules for those who knowingly endanger others must always be more strict than for those who knowingly take their own risks. But AIDS prevention requires all of us to be more accepting of our sexuality, not less, and to be more deliberate, careful, and responsible in its expression.

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Comments on Currents

AIDS in Rural Areas: Challenges to Providing Care

Kathleen A. Rounds

This study was conducted to examine the development and provision of services to persons with acquired immune deficiency syndrome (AIDS) and their families in rural areas and barriers to the delivery of care. The 15 respondents in this study coordinated or provided services to persons with AIDS and their families, and most of the persons with AIDS were gay men; thus, the focus of this article is rural gays with AIDS. However, all persons with AIDS in rural areas experience many of the same barriers to care, particularly barriers related to the stigma of having AIDS.

Rural Characteristics that Affect Care of Persons with AIDS

Some authors base their definition of rural on demographics, others on a way of life or value system.[1] For the purposes of this article, *rural* refers to

> the environmental surroundings, the social systems, and the people who reside in areas that have relatively low population density, usually either in the country or in small towns or villages.[2]

To understand the experience of AIDS and the challenges to providing AIDS care in rural communities, one first must examine characteristics unique to rural areas that influence social and health care.

Rural America is not homogeneous; however, rural areas have certain characteristics in common. Compared with their urban counterparts, rural residents consider religion and the role of the church to be very important in community life, hold more traditional moral values, expect greater conformity to community norms, and are less tolerant of diversity.[3] Rural residents also believe that the community should take care of its own and provide care through primary relationships and informal networks, rather than through formal bureaucratic systems, in part because access to social and health services is greatly limited.[4] These characteristics influence the delivery of health and social care to persons with AIDS and their families living in rural areas.

Geographic isolation, one characteristic of rural areas that affects care of persons with AIDS, limits access to social and health services for most rural residents. Particularly in the rural South, poverty, the maldistribution of health care providers, and lack of transportation and services make obtaining health care difficult for residents.[5] In addition, rural areas contain more than half of the nation's substandard housing units.[6] The delivery of in-home health services to persons living in such housing can be a complicated task.

Another characteristic of rural areas is that residents rely heavily on social networks to provide social support and other services that more formal agencies often provide in urban areas.[7] Although changes in rural areas, such as out-migration associated with lack of employment opportunities, have begun to erode these support systems, they still are powerful providers of social and health care because formal services are so limited.[8] Strong social networks usually are perceived as a positive aspect of rural communities, but they are not value-free and can stigmatize as well as protect members. Wodarski notes, "because of the closeness of social networks in rural areas, individuals who exhibit deviant behaviors are labeled more readily."[9] Waltman describes the helping among members of natural networks as helping those who are "deserving," defined as "compliant with unwritten community moral codes in areas of money management, sexual conduct, alcohol or drug abuse, and the work ethic."[10] Thus, persons with AIDS and their family members may receive much less support from networks than if they were coping with another disease such as cancer, particularly if AIDS was contracted through intravenous drug use or "unacceptable" sexual behavior.

Religion is another important characteristic of rural communities.[11] In rural communities, religious values and groups affect other aspects of community functioning such as the delivery of community health and social services.[12] Congregations act as support networks for people in need and help people to define their problems, discuss their fears, get assistance, and build support systems and coalitions. The church also could prevent disease by educating and advising members about health risks and available services and by promoting healthy community environments and life-styles.[13] However, because the prevalence of AIDS still is low in rural areas, the capacity of churches to provide care to persons with AIDS and their families and to educate the community about AIDS has yet to be tested.

Lack of tolerance for diversity is a final characteristic that affects care of persons with AIDS in rural communities. A noted author concluded,

> If otherness became okay in rural America, it is possible we could face the pain of the world better than we do.[14]

In most rural communities, otherness includes being gay. To avoid stigma, rural gays must assume low visibility, avoid publicly declaring their sexual orientation, and fit into "routine family and community life."[15] This difficult task takes a psychological toll that is particularly great when gay individuals internalize the negative attitudes toward homosexuality that exist in most rural environments.[16] Some gay individuals choose another option—to leave rural communities to live in a more accepting, usually urban, environment—and thus the family and community maintain their denial of the existence of homosexual individuals among them.[17] Unfortunately, staying and assuming low visibility or leaving and becoming invisible never force the community to deal with differences and so reinforce the distance between the gay person and the rural community.[18] Because these two mechanisms of denial are upset when a gay person who left a rural community is diagnosed with AIDS and returns home to be with his family, the community and family must confront their feelings about homosexuality as they deal with their fears about AIDS.

Among the problems of being gay in rural America is limited access to support systems, which contributes to a deep sense of isolation among rural gays.[19] Support is difficult to access for several reasons: because without a large, visible, and diverse gay community, gays must depend upon nongays for support; because professionals in the formal support system may not understand or be responsive to the needs of gay clients; and because major informal community support systems, such as family or church, may exclude gays if their sexual orientation is known.[20] Also, in rural environments, where conforming to traditional institutions is expected and where

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the church plays a major social role, many gays find themselves in conflict with religious norms and unwelcome in the church community.[21] Thus, lack of tolerance for diversity greatly reduces the positive supportive functions of rural social networks and churches, and persons with AIDS (particularly if they are gay) and their families may encounter hostility and neglect rather than support.

Study Methodology

This study was designed to examine challenges to care for persons with AIDS and their families. During a four-month period in 1987, in a Southeastern state in which 48 percent of the population is rural, 15 persons who were coordinating or delivering services to persons with AIDS and their families were interviewed.[22] The sample was derived using the "snowball" method.[23] That is, a contact in an AIDS service organization recommended several individuals who were knowledgeable about support services for persons with AIDS in rural areas, who in turn nominated other potential respondents. The total sample included social workers, nurses, health educators, administrators, and lay volunteers from a variety of organizations such as hospitals, AIDS support organizations, hospice and home health care agencies, members of local and state AIDS task forces, and public health and social service departments. Although the sample did not necessarily represent all providers working with persons with AIDS, the sample did represent a wide range of organizations, professionals, and geographic areas. Information and minutes from meetings of the state AIDS task force, a statewide AIDS conference attended by the author, and discussions with individuals familiar with rural human services also inform the findings.

The response rate was 100 percent, as all persons asked to be interviewed agreed to participate. The structured interviews lasted from one-half hour to two hours. Interview questions were developed based on the literature discussed earlier in this article. The interviews focused on barriers to services for rural persons with AIDS and their families and also covered the following general areas: the respondent's role and experience in working with rural persons with AIDS, problems experienced by persons with AIDS living rural areas, issues in providing care to persons with AIDS in rural areas, and strategies to improve the delivery of services.

The data were coded and analyzed using techniques for working with qualitative data described by Chesler.[24] Pattern coding also was used to analyze the data.[25] This technique involved first coding the data and then grouping segments of the data into clusters. These clusters then were contrasted and compared to discover themes related to challenges to providing care. Several themes emerged as challenges to providing care to persons with AIDS and their families living in rural areas.

Challenges to Providing Care

Structural Factors

First, structural factors such as lack of services and geographic distance to services affect the provision of health and social care to persons with AIDS in rural areas. A major structural problem for most rural persons with AIDS is the distance to health care facilities that treat AIDS patients. Transportation to a secondary or tertiary care hospital or to a medical clinic in an urban area, lodging, and missed work time for the caregivers are expensive and time-consuming as well as extremely difficult for persons with AIDS who are experiencing pain and discomfort. These factors, coupled with a hesitancy to use medical care or limited knowledge of the disease process associated with AIDS, prevent people with AIDS and their families from seeking the care that they need.

One respondent-provider also described the structural problem of providing *buddy support* (a volunteer from an AIDS service organization) as a "geographic nightmare... it's hard to send out a buddy when the person lives almost a hundred miles away on two-lane roads." In many cases, contact with a buddy must be by phone because of geographic distances; agencies with AIDS hotlines overcome some of the geographic barriers to support.

Distance also makes discharge planning particularly difficult, because it compounds the difficulties for hospital staff in dealing with the community agencies' problems or inexperience in providing care to persons with AIDS. In these interviews, hospital staff expressed concern about quality of home care and confidentiality once the persons with AIDS were discharged to communities, and respondents from community agencies reported that hospital staff were unaware of the limitations in some rural communities and had unrealistic expectations of what services could be arranged with short notice. For example, poverty and poor housing in some rural areas make the delivery of home health services very difficult; with no refrigeration and running water in some homes, administration of intravenous antibiotics that require refrigeration becomes a complex procedure.

Confidentiality

As a second theme that emerged from th interviews, every respondent identified confidentiality and the fear of disclosure as affecting the delivery of services to persons with AIDS. Respondents consistently stated that "in rural communities everyone knows everyone, and everyone knows your business." Several respondents described incidents that involved breaches of confidentiality; for example the consequences of such a breach by workers in a local lab was that the caregiver of a person with AIDS was asked to leave her church. Several respondents stressed asking each person with AIDS or family to specify what information could be disclosed and to whom in the community the service provider could obtain needed support and still protect confidentiality.

Respondents reported that persons with AIDS dealt with their concerns about confidentiality in various ways. Some relied heavily on AIDS hotlines for information and support rather than depend on people in their own small communities. Other persons with AIDS chose to receive all medical care in a tertiary hospital even if it required traveling long distances. Others prolonged seeking help as long as possible. Unfortunately, fear and anxiety about disclosure prevent people from receiving critical services and isolate them at a time of tremendous need. The fear that confidentiality might be broken also reduced the willingness of persons with AIDS and their families to share their experiences with others in similar circumstances, thus cutting off an important avenue of support:

> We had two patients in the unit from the same town. Neither family would tell the other that their family member had AIDS; they told each other that it was something else.
>
> Family members have told us that they are willing to talk with other families who are dealing with AIDS, but not in a group, only on a one-to-one basis, and they want us to arrange the contact.

Concern that "others in the community will find out" prevents families from grieving openly about the death of a loved one from AIDS. Efforts to maintain secrecy about the cause of death interfere with family members' attempts to explore their own pain, give meaning to their experience, and ultimately resolve a range of confusing feelings that may surround a death from AIDS. Respondents reported:

> It's not uncommon for families to tell their neighbors, their minister, and eve

other relatives that their son is dying of cancer, not AIDS.

> I went to the funeral of a patient that I took care of, and there were all these people from this small town there, and his mother came up to me in tears and said "I'm so glad you're here, you're one of the few people who really knows that he died of it."...How's this mother ever going to work through her grief over her son's death, if she can't talk about what he died of?

Closely related to the issue of confidentiality are the two other themes that emerged as challenges to providing care to people with AIDS: (1) fear of AIDS contagion and (2) homophobia. If these two attitudes did not exist, confidentiality might be of less concern than it is.

Fear of AIDS Contagion

Most respondents stated that it was difficult to arrange for services in certain communities because of the fear of AIDS contagion. Some hospices and home health agencies would not accept referrals because they had not yet developed staff policies and training for working with persons with AIDS or they did not have volunteers who were willing to make home visits. Respondents could not determine if this hesitancy to care for persons with AIDS reflected lack of awareness about the need for services, agency denial that AIDS had spread to their community, or fear of contagion. Arranging for county social services department chore workers or homemakers to work in homes of persons with AIDS also presented problems.

Respondents reported that some community residents believed that their risk of infection was increased by receiving care from individuals or agencies that provided care to persons with AIDS. Thus, those who work with persons with AIDS in rural areas also experience the stigma of AIDS, and this high-visibility stigma affects service delivery in various ways:

> None of the doctors here want to take care of AIDS patients, they either don't have the expertise or don't want it known that they treat AIDS patients in their practice for fear that other patients will not use them.
>
> We don't openly advertise that we treat AIDS patients, because then there will be a lot of publicity about it, which may affect other referrals or volunteers....The community prefers to deal with this issue with denial....They won't openly support you nor will they try to stop you as long as you don't broadcast what you're doing.

Homophobia

Because AIDS was associated with the gay male community so early, separating homophobic reactions from reactions associated with fear of AIDS often is difficult. However, respondents identified incidents in which homophobia clearly interfered with persons with AIDS' receiving support; especially the many gay persons with AIDS who had lived in urban areas and returned to their families after they were diagnosed with AIDS. Respondents stated that in some families the person with AIDS was allowed to move home only if he agreed to cease contact with gay friends and lovers, thus increasing the person's sense of isolation. One respondent said that the most difficult task in working with gay persons with AIDS was to prevent them from internalizing the homophobia prevalent in rural communities. Gay persons with AIDS who return to rural communities at a time of particular vulnerability to self-blame often confront the belief of many in the community that "AIDS is God's punishment for your sins."

Homophobia also has forced AIDS service organizations to struggle with how they identify themselves—as a gay organization providing services to all persons with AIDS or as an AIDS organization. Such organizations are aware that their identity influences funding, community support, and referrals. One respondent, who was a volunteer for an AIDS service organization, noted that even though the organization worked very hard to be identified as an AIDS organization, it often was perceived as a gay organization that served persons with AIDS, which reduced the number of referrals of nongays:

> We don't get the referrals that we should, because if the person isn't gay, they (the referring agency) think that the referral isn't appropriate. Just recently a wife of a [person with AIDS] contacted us for information on home precautions safe sex. She said that she wished that she had known about us earlier, because the information was very helpful. We were aware that the primary agency providing care had not told the wife about our organization because her husband wasn't gay.

In contrast, some AIDS service organizations have chosen to remain clearly gay-identified; they believe that providing a needed community service is one way to project a positive image and to bridge the gap between the gay and nongay communities. Several respondents stated that when health care providers deal with gay-identified men and women in professional roles and gay-identified human service organizations, the providers are forced to reexamine their stereotypes. Several of these organizations have been asked to present in-service training on homophobia to medical center staffs.

Enhancing Service Provision

The social work interventions proposed in this article focus on coordinating, strengthening, and expanding existing community resources and networks rather than creating new delivery systems. Structural barriers to health and social services in rural areas are longstanding and likely will not be overcome without major economic changes and new directions in health care policy and delivery. Furthermore, because the number of AIDS cases in rural areas will remain low relative to the number in urban areas, developing separate agencies that provide services to persons with AIDS is not practical in small towns. Therefore, existing community agencies, such as county public health and social service departments, and local home health and hospice agencies will need to work closely with informal community networks to provide AIDS care.

One way to reduce the effects of the geographic, cultural, and educational distance between the urban hospital and the rural community is to develop mechanisms to promote continuity of care. Coordination between hospital social workers who perform discharge planning and community agency social workers who function as case managers can be increased through education and the development of follow-up systems. Rural social workers can educate hospital social workers about the strengths, limitations, and indigenous care systems of rural communities; hospital social workers can share their expertise about the psychosocial dimensions of AIDS and the care needs of specific patients and families and explain the organizational pressures they experience to arrange for timely discharge. Follow-up systems should provide feedback to the hospital social workers about the outcome of discharge planning and to the community social worker about the hospital treatment plan when the patient eventually is readmitted.

Concerns about confidentiality need to be dealt with in the context of improving continuity of care and as a critical component of discharge planning. Through collaborative efforts between the hospital and community social workers, the importance of confidentiality should be reinforced with community agencies. Breaches of confidentiality in the community can be dealt with quickly by the community social workers. Because community workers are knowledgeable about rural norms and social networks, they can work closely with the person with AIDS and the family to decide who in the community should be told about the AIDS diagnosis and how the information can be shared to mobilize support and protect confidentiality.[26]

Through support and education, social workers in the hospital and in the community can strengthen existing informal and formal networks that provide care to persons with AIDS and their famlies. Social workers need to explore with families ways that they can enlist help from their network. One strategy is for the social worker to bring together members of the network selected by the person with AIDS and the family to explain the person's diagnosis, prognosis, and care needs and to suggest ways that extended family, friends, and neighbors can provide support. Newmark and Taylor suggest another social work task in assisting families in obtaining support is to teach families how to get services from community agency staff who may have no previous experience with persons with AIDS and may feel uncomfortable and hostile.[27]

Social workers also should prepare agencies to provide humane and compassionate care to persons with AIDS and their families. An important preliminary step in this process is to respond to the stigma attached to persons with AIDS and to agencies working with them.[28] One of the roles of rural social workers is to reduce stigma that interferes with clients receiving services.[29]

First, however, social workers need to educate themselves about AIDS and deal with their own fears and homophobia. When asked about AIDS education for health care professionals, a health care worker interviewed for the study discussed in this article stated, "to begin with, they need the same education as lay people; they're not immune to prejudice and fear."

Recognizing and working with the fears and homophobia of staff in social service and health care agencies is the next step in this educational process. Also, acknowledging the effects that caring for AIDS patients will have on staff, particularly in hospice and home health agencies, is crucial.[30] Hospice workers who traditionally have cared for older people dying of cancer will need considerable preparation and ongoing support to deal with the stress of caring for young people who are deteriorating mentally and physically. Social workers, nurses, physicians, and health educators from larger communities who have dealt with staff concerns about providing humane care to persons with AIDS and about AIDS transmissibility can be consulted by local home health and hospice staffs who are developing agency policies and procedures and in-service education. However, providing information will not be enough; ongoing sessions that encourage staff who work with persons with AIDS to openly express their homophobic attitudes and fears about AIDS contagion will be necessary. For people to confront and overcome their fears, they need a forum to discuss them in an atmosphere that promotes honesty and openness.[31]

When existing networks are unable or unwilling to provide care, social workers will need to build a network of people in the community who will provide support to persons with AIDS and their families. According to several respondents in the study, a one-on-one approach works better than community forums in smaller towns and with some cultural groups, because the approach does not call attention to the problem or "create a stir" and fits in with the "way people do things around here." By cautiously identifying individuals in the community and in health and social service agencies who might be interested in working with AIDS patients, social workers can develop networks to provide support and assistance to families caring for persons with AIDS. Social workers also might involve potentially supportive ministers and church communities, especially if the person with AIDS or the family belongs to the local church.

Another approach to network building is to invite selected community members to an AIDS educational session. Sheehan describes how a rural hospice successfully used this approach.[32] The hospital presented an educational program before persons with AIDS were in the community so that people could express concerns and have their fears and questions addressed. This hospice not only provided leadership but also confronted the stigma attached to an agency that works with persons with AIDS. By asking people to reframe their definition of community—not as "us and them" but instead as "they are part of us; we are all in this together"—the hospice challenged assumptions that difference deserves a different level of care. Residents who are asked to confront their fears as a community and to reexamine their value system in light of change in their community will be less likely to use denial of the problem to keep AIDS out of the community. When a respected agency brings a community together to address AIDS concerns and publicly states a commitment to provide care to AIDS patients, community fear and stigma are confronted, and thus health care providers can help rural communities to provide sensitive social and health care to persons with AIDS and their families.

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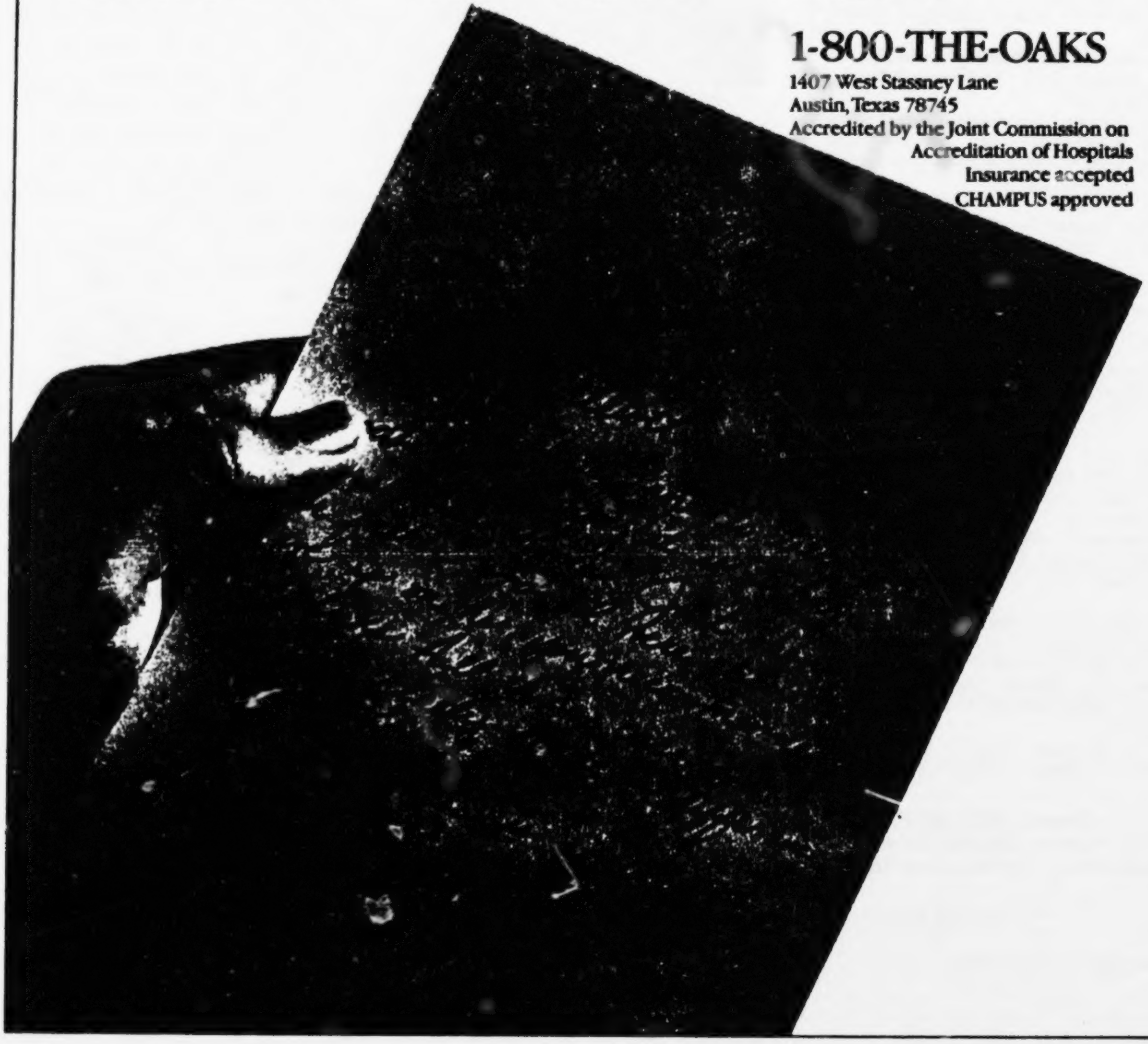

Briefly Stated

An Approach to Coping with Anxiety about AIDS

Irwin Krieger

At times, anxiety can be a helpful, motivating response in a dangerous situation. Lately, however, there has been a noticeable increase in anxiety related to acquired immune deficiency syndrome (AIDS). Much of the concern is because currently there is no cure for this disease and because there is no vaccine to prevent a person from becoming infected with the virus.

This article describes a stepwise counseling approach for assisting persons with heightened anxiety about AIDS and ways to handle fears about the sexual transmission of AIDS. The counseling approach emphasizes five steps: (1) getting accurate information, (2) assessing one's fear of prior exposure, (3) learning to protect oneself and others, (4) gathering strong peer support, and (5) addressing related issues.

Getting Information

The first step in confronting the AIDS epidemic is to get accurate information. For persons coping with AIDS-related anxiety, their knowledge base should include information about the signs and symptoms of AIDS and AIDS-related complex (ARC), how human immunodeficiency virus (HIV; the virus associated with AIDS) is transmitted, and methods for reducing the risk of transmission.[1] Many individuals exhibiting heightened anxiety about AIDS are overinformed, having read and viewed sensationalized media presentations. However, as they seek to relieve their anxiety, these persons find that it only increases. Beyond establishing an adequate, accurate, and up-to-date knowledge base, such individuals are advised to refrain from reading about AIDS and watching TV shows on the subject until they have gained some control over their anxiety.

The best sources for reasonable, updated information on AIDS and reducing one's risk of infection are community-based organizations like AIDS Project New Haven, in Connecticut, and Gay Men's Health Crisis, in New York. Most of these organizations have established hotlines and provide pamphlets with basic information on AIDS. The hotline responses are caller-specific and reflect the most current information; also relevant written materials can be sent out on request.

Assessing One's Risk Factor

Step two in confronting AIDS-related anxiety is to make a realistic assessment of one's own risk of prior exposure to HIV. This assessment may seem to be a difficult task, as the information about sexual transmission of the virus is presented in terms of relative risk only (that is, which sexual behaviors are more or less risky). However, with the help of an objective consultant, an individual can place him- or herself on a continuum of risk from low (few sexual contacts, safer sex precautions observed) to high (many partners, frequent high-risk behaviors). A sense of one's risk of previous exposure is useful in providing reassurance to persons at low risk, while allowing others to face the more difficult situation realistically.

Generally, the assessment should not include HIV antibody testing. To date, these tests have only proven to be controversial and inconclusive. The results are useful only in extremely limited situations (such as for couples contemplating having children).[2] For the most part, a person can test negative or positive, which means that the person has or has not been exposed to the AIDS virus. Any person contemplating getting the antibody test should behave as if he or she and all potential sexual partners may be capable of transmitting HIV. If effective preventive treatments are developed for those who test positive for the AIDS antibody, recommendations about taking the test will change.[3] Those who choose to be tested should do so in a confidential setting, with no names used and with pre- and posttest counseling.

Initial reactions to the AIDS epidemic often are characterized by denial or hopelessness. These attitudes are unrealistic and counterproductive. They support the point of view that nothing can or should be done, that the problem is out of control completely, and that people should either throw all caution to the wind or else give up and withdraw. Thus reckless or depressive behaviors as a result of the AIDS epidemic are more apparent. These attitudes and behaviors only serve to heighten anxiety about AIDS, and may lead to increases in risky behavior. To the contrary, these attitudes and behaviors must be confronted as a step toward learning to cope with the anxiety. By eliminating denial and hopelessness, one can begin to face the anxiety and focus on safe sexual practices.

Protecting Oneself and Others

Having tackled these attitudinal roadblocks, the individual with heightened anxiety can focus on the third step: ensuring protection of self and others. Implementing safe sexual practices can be problematic. Getting to know one's sexual partners before engaging in sex is important in that it allows for more comfortable discussion of safe sexual precautions beforehand. Partners can explore different sexual possibilities to find enjoyable and safe activities.

The recreational use of drugs and alcohol is common in the sexual arena. Allowing alcohol or drug use to impair judgment regarding precautions against AIDS can be a serious problem. In addition to limiting or abstaining from using drugs in situations conducive to sexual encounters, it is important to assess any routine drug or alcohol use for the risk of becoming addicted. Furthermore, sharing needles in intravenous drug use is a known route for transmission of HIV. Although needles can be sterilized or not shared, intravenous drug use also should be addressed as an addictive problem that requires treatment.

Good health practices also are important. Good nutrition, regular exercise, and stress reduction with relaxation training contribute to a more positive self-image and a lessening of depression and anxiety.[4] A feeling of better health certainly is reassuring, and minor somatic complaints that trigger AIDS fears are less likely to occur.

A comfortable relationship with a competent medical provider is essential. The provider must be knowledgeable about AIDS and open-minded regarding the individual's life-style and sexuality. Many persons with heightened anxiety about AIDS have gone from doctor to doctor with inconclusive complaints. The symptoms of ARC, such as fevers, swollen glands, weight loss, night sweats, and diarrhea are common to many illnesses.[5] These symptoms only suggest a possible diagnosis of ARC if they persist.

Peer Support

Gathering peer support is the fourth important step in reducing anxiety about AIDS. Peers can discuss their anxieties in a manner

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that is mutually supportive, thus avoiding the pitfalls of denial and hopelessness. They can gain experience talking about safe sexual practices to feel comfortable discussing their concerns with a potential sex partner. Also, they can support each other in making positive, healthy changes in their life-style.

In a group of gay men with heightened anxiety about AIDS, the author observed a rapid drop in anxiety after members shared their fears. Previously, their friends and associates had told them their fears were ridiculous overreactions—responses that only served to heighten their anxiety. They believed their fears were understood and their anxiety appreciated. Concerns about confidentiality, however, are particularly high for this group, as they are already feeling quite vulnerable. Hence, the feelings of vulnerability must be kept in mind when designing group interventions, whether as self-help or psychotherapy.

Addressing Related Issues

A variety of unresolved personal issues often are displaced onto anxiety about AIDS. Addressing these issues is the fifth step that helps to reduce the overall level of anxiety. Four major concerns are: (1) guilt over sexual or drug use behavior, (2) addictive attachment to anonymous or dangerous sex, (3) secrecy about a person's at-risk status, and (4) homophobia.

The guilt feelings are a major component of severe anxiety. Because the spread of AIDS has been attributed to sexual promiscuity and drug use primarily, it is easy for those at risk of infection (as well as those who have been infected or are ill with the disease) to view AIDS as a punishment for these often-condemned behaviors—a point of view religious spokespersons and others have endorsed. Gay and bisexual persons, intravenous drug users, and promiscuous individuals often do not have nonconditional support from family and friends. Without an opportunity for respectful, nurturing responses, the individual is likely to amplify the actual or anticipated disapproval from others and direct it inward. In the context of the AIDS epidemic, these feelings are transformed easily into expectations of illness-as-punishment. When given a chance to reveal these sexual or drug-use behaviors in a supportive environment, such as Alcoholics Anonymous or Narcotics Anonymous, gay community meetings, individual or group therapy, or conversations with a sympathetic friend, family member or associate, a person begins to relinquish some of these guilt feelings and negative self-assessments.[6]

Becoming addicted to the ease and thrill of anonymous or dangerous sexual activity is a widespread problem.[7] In the context of the AIDS epidemic, this is a double-edged problem, in that these activities can present a high risk of HIV infection because of the increased number of different contacts and the reduced likelihood of taking precautions. The attitudes motivating this behavior can include low self-esteem, fear of intimacy, sexual guilt, difficulty delaying gratification or tolerating anxiety, and self-destructive impulses that make the sense of risk attractive. For gay men and lesbians, the fear of being seen with a person of the same sex repeatedly can be a deterrent to seeking ongoing involvement with one person.[8] These concerns are best addressed in a supportive and confidential setting.

The response to AIDS in the United States has been influenced overwhelmingly by prevailing attitudes toward the two groups most heavily affected, namely gay and bisexual men and intravenous drug users. As people learn more about how AIDS is transmitted, they will understand that it is not the individuals, rather specific behaviors (most notably unprotected anal or vaginal intercourse and sharing needles) that account for the spread of the disease. Individuals whose at-risk status remains a secret from their sexual partners (as is frequently the case with bisexual men and intravenous drug users) experience inner conflict and often increased anxiety in relation to these sexual partners. On one hand is the perceived need for secrecy to protect themselves from rejection by a partner and from the risk of others finding out about the secret status. On the other hand is a sense of concern for and obligation to this partner, and the desire to be honest about the possible risk. Today it is possible to insist on safe sexual precautions without raising a partner's suspicions in most situations, so that an at-risk individual has the option of offering some protection while maintaining secrecy. For married people having secret extramarital relations, safe sexual precautions with the spouse cannot be justified without admitting to the behavior. In the case of gay and bisexual men and women who are married, the conflict between marital commitment, interest in having an intact family, and sexuality can be resolved in a number of ways, once the person explores his or her true feelings and relational conflicts.[9] For those who have engaged in high-risk sexual activity secretly, HIV antibody testing may be a helpful step once the generalized anxiety or panic disorder and identity issues have been at least partially resolved.

Homophobia—the irrational fear and hatred of homosexuality—is a prime factor in our society's response to the AIDS epidemic.[10] In helping others to resolve their anxiety, social workers must be alert to the many ways homophobic attitudes create or augment low self-esteem, fear of intimacy, sexual guilt, self-destructive impulses, addictive sexual behaviors, and secrecy conflicts. At the same time, social workers, health care workers, and others concerned about AIDS should address homophobia when it affects decisions regarding AIDS education, research, and the provision of services to people with AIDS and ARC.

The stepwise counseling approach presented here provides a framework for addressing anxiety about AIDS and helping others overcome it. In clinical work, anxiety about AIDS may be a client's presenting problem or an issue of secondary importance. It may be a motivating factor in a pattern of self-destructive behavior. The fear of AIDS affects anyone with a risk of exposure to HIV to some degree. When that fear becomes unmanageable, intervention is needed.

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Public Health and the Law

The Ethics of Screening for Early Intervention in HIV Disease

CAROL LEVINE, MA, AND RONALD BAYER, PHD

The treatment of AIDS (acquired immunodeficiency syndrome) and HIV (human immunodeficiency virus) infection has entered a new, more hopeful era, marked by incremental advances in therapy rather than heralded by a single, dramatic breakthrough. For those ill with AIDS itself, the prognosis remains grim. But many clinicians, public health officials, patients, and AIDS activists are now convinced that early treatment of asymptomatic HIV infection is beneficial in preventing or delaying the onset of illness.

The voices supporting this view are many and varied. Drs. Robert R. Redfield and Donald S. Burke, of the Walter Reed Army Institute of Research in Washington DC, were early advocates of HIV antibody testing for prompt diagnosis of HIV infection. In a recent summary, they stated: "Prompt diagnosis of HIV infection enables the patient to receive optimal medical care from the earliest moments of the disease. Such care can often prevent complications from developing or getting unnecessarily out of hand."[1]

From a community-based perspective, Project Inform, a San Francisco information and advocacy group, gives its constituents this remarkably similar "Basic Message":

> Get tested, anonymously.
>
> If positive, consider anti-viral treatment.
>
> Monitor T4 cells quarterly, charting the trend.
>
> If the trend of T4 cells is downward or falls consistently below 500, consider both anti-viral therapy and immune boosting therapy.
>
> If the trend of T4 cells falls below 200, consider prophylactic (preventive) treatment against *pneumocystis* (aerosol or oral forms).[2]

After a review of available evidence, the United States Public Health Service has issued the same advice.[3] The San Francisco AIDS Foundation and the Gay Men's Health Crisis in New York launched campaigns to encourage everyone at risk to be tested voluntarily in order to take advantage of early medical intervention.[4] Dr. Anthony S. Fauci, director of the National Institute of Allergy and Infectious Diseases, has said that there is "no question" that it is now medically advantageous to know one's HIV status.[5] In the most sweeping recommendation, Drs. Frank S. Rhame and Dennis G. Maki recommended HIV testing "to all US adults under the age of 60 regardless of their reported risk history."[6]

Testing patients with symptoms suggestive of HIV disease under conditions of informed consent as part of a diagnostic workup has never posed ethical problems. However, when HIV antibody testing became available in 1985, there were no clinical grounds for testing asymptomatic individuals, although there were public health reasons to encourage testing. Substantial changes in therapeutic prospects and the anticipation of even greater advances to come have fundamentally altered the context of the discussion about HIV antibody testing. Because of these changes, it is critical at this point to reconsider the ethics of screening for HIV infection.[7]

It is precisely when medicine's capacity to enhance patient welfare appears to be increasing that there is a danger that important ethical concerns can be overridden or disregarded. This is especially so in the case of AIDS—a disease that will continue to exact an enormous toll in human suffering for the foreseeable future and that continues to have a social and cultural impact far beyond the numbers of people affected.

In this article we discuss the ethical aspects of screening and testing to detect asymptomatic HIV-infected individuals for clinical purposes. Adopting customary usage, we define "screening" as the application of the HIV antibody tests to populations and "testing" as the application of that procedure to individuals on a case-by-case basis.[8] It is important to distinguish among the many potential justifications for screening such as prevention of transmission, infection control, epidemiological surveillance, and medical care. We believe that all justifications for screening should be evaluated independently and should not be masked by the language of potential therapeutic benefit to the individual.

Evidence for Early Intervention

Earlier, more accurate identification of seropositive individuals would ideally make it possible to offer them the benefits of: a) inhibition of viral replication or improvement of immunological status; b) better management of symptoms or prevention of the onset of opportunistic infections; c) better general health care.

Identification of True Seropositives

The combined ELISA* HIV antibody test and the supplementary Western blot provide a high but not absolute level of accuracy in identifying seropositive individuals.

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*enzyme-linked immunosorbent assay

Indeterminate Western blots occur in a small percentage of samples that are repeatedly reactive on ELISA tests, making necessary further testing for viral culture.[9] Recent evidence has indicated that antibody response may be delayed, in some cases as long as 35 months, in some unknown proportion of infected individuals, leading to false negative results.[10]

The level of accuracy that can be obtained with adults does not yet apply to infants. Infants born to infected mothers have maternal HIV antibodies, which may indicate true infection or which may disappear up to 15 or 16 months after birth. Recent studies indicate that from 20 to 50 percent of infants with HIV antibodies are truly infected, a decrease from earlier estimates.[11] Dr. Stephen C. Joseph reported during the Kenneth D. Blackfan Lecture in June 1989 that the most recent evidence from New York City shows a 29 percent transmission rate from infected mother to fetus.

New techniques for the direct identification of viral infection have been reported, primarily the polymerase chain-reaction technique (PCR).[12] This technique can detect the presence of HIV provirus DNA (deoxyribosenucleic acid) sequences as long as six months prior to seroconversion from negative on a Western blot. PCR may be of assistance in clarifying the meaning of indeterminate Western blots, but it is still highly experimental, expensive, and difficult to perform except under specialized laboratory conditions. Limited studies with infants show promise; in one study of seven infants, positive results proved reliable (the babies later developed AIDS or symptoms of HIV infection), but negative results are much less reliable and may miss as many as 60 percent of infected infants.[13] PCR is not, and may never be, useful as a mass screening tool. An enhanced ability to detect truly infected individuals is relevant because of the potential to provide early therapeutic benefit. At this juncture infected adults but not infected infants can be reliably identified.

Inhibition of Viral Replication

Recent evidence indicates that early intervention may inhibit viral replication in some people. A group led by Frank de Wolf and Jan Mulder of the University of Amsterdam reported in February 1988 on the treatment of 18 asymptomatic men with longstanding HIV infection with low doses of zidovudine (AZT), either alone or in combination with acyclovir. They found that zidovudine has "an inhibitory effect on viral replication . . . in blood and (in one subject) the central nervous system. . . ."[14] Later that year they reported that only two of 24 healthy seropositive men treated with AZT needed blood transfusions, compared with 20 to 50 percent of patients with AIDS. Furthermore, the side effects of zidovudine in asymptomatic patients were "mild, transient, and infrequent."[15] In a study presented at the V International Conference on AIDS in June 1989, the Amsterdam group reported that "even with early zidovudine treatment and considerable suppression of HIV-Ag production disease progression can still occur."[16] In August 1989 an AZT trial was stopped after data showed that the drug retarded the development of AIDS in mildly symptomatic people.

Several studies of asymptomatic, HIV-positive persons are underway at the National Institutes of Health (NIH) and in the United Kingdom and France.[17] The largest NIH study is a Phase III, placebo-controlled study consisting of two doses of AZT. This trial, which began recruiting subjects in 1987, is a three-year study; it originally expected to enroll 1,562 subjects, but that number was increased to 3,000. Two weeks after the AZT trial with mildly symptomatic people was stopped, the arm of the trial testing AZT in people with mildly impaired immune systems was also halted, when data showed that those taking the drug were half as likely to develop symptoms as those taking a placebo.[18] Other, smaller NIH studies are also underway, involving zidovudine as well as other drugs.

In his review of the development of early intervention strategies against HIV infection, Dani Bolognesi concluded on a hopeful note. Nevertheless he cautioned that "the emerging picture is far from clear . . . One can [however] begin to visualize certain lines of investigation to pursue" for more definitive answers.[19]

Prevention of Opportunistic Infections

Clearly the symptoms of the opportunistic infection associated with AIDS are better managed today than in earlier years. The most dramatic difference is in the management of *Pneumocystis carinii pneumonia* (PCP), the most common infection and the one most often associated with early death. Sulfa-based drugs are used to prevent recurrences. However, many patients have allergic reactions to this class of drugs.

Aerosolized pentamidine had been widely used to prevent the recurrence of *Pneumocystis*, even before the Food and Drug Administration (FDA) approved its use under a Treatment IND (investigational new drug) for this purpose. The FDA also approved the drug for patients with 200 or fewer T4 helper cells per cubic millimeter, who are at high risk for developing PCP.[20] The US Public Health Service recommendations on primary prophylaxis (for individuals who have not had an episode of *Pneumocystis*) are largely based on extrapolations from evidence from trials of secondary prophylaxis.

Improved General Health Status

A clear benefit of early identification of HIV infection is the opportunity to test for other diseases, such as tuberculosis and syphilis, and to institute appropriate prophylaxis or therapies. Moreover, many persons who learn they are HIV positive are motivated to engage in healthier lifestyles, changing their diets, exercising more, and reducing cigarette, alcohol, and drug use. There are no studies to support the belief that these changes affect the progression of HIV disease, but many people who have altered their lifestyles report an enhanced feeling of control over their lives and higher energy levels.

Potential Benefits and Risks

Since HIV becomes part of the individual's genetic material, only a therapy that eliminated the virus from DNA or that permanently inhibited viral expression could be considered a cure. At best, early therapeutic intervention at this point can offer an individual longer disease-free intervals, a better quality of life through symptom management, and the hope that the longer one lives the greater the likelihood that even better therapies will be available. These are substantial benefits.

As is the case in adults, there is no proven therapy for asymptomatic HIV infection in newborns. However, knowing that an infant is potentially infected may make possible the aggressive treatment of infections that might otherwise be treated routinely. The more vigilant medical monitoring of such infants could prove especially beneficial since the majority of them are from poor and minority backgrounds and thus vulnerable to many other ailments that are common in economically deprived areas. Moreover, special vigilance can act as a counterbalance to some of the more general problems of health care in poor communities, including access and the lack of a single primary caregiver who can follow the infant's progress.

Providing patients or their guardians with such medically relevant information enhances autonomy. However, the uncertain nature of the information about possible infection can also create situations in which healthy, uninfected infants are subjected to aggressive and potentially risky interventions. In addition, there is no assurance that identified infants will actually receive special attention; according to the New York City Human Rights Commission, some mothers have encountered difficulties in obtaining health care for HIV-infected babies.

Innovative therapies currently available carry substantial risks. Early intervention in HIV infection is not analogous to a short course of penicillin to treat syphilis. All the drugs that are believed to have an anti-viral effect also have toxicities. These may be mild or moderate in low doses; long-term toxicities are unknown. Furthermore, some viral strains are already becoming resistant to drugs.[21] Because there are so many unanswered questions about the long-term consequences of taking anti-viral drugs and because not everyone is benefited, all such regimens must be evaluated on a continuous basis.

The method of administration may also be a burden. Drugs may have to be taken orally every few hours or intravenously. Over time, this regimen can become onerous to a healthy person. Presumably, any regimen that was effective would have to be continued for an indefinite period. The asymptomatic person may also find the psychological burdens of becoming a "patient" restrictive. All the regimens will require frequent monitoring by physicians or nurses as well as accurate self-reporting by the patient. Administration of some therapies to newborns may require hospitalization, intravenous infusions, and the attendant medical and psychological risks.

There are also potential, well-documented social risks to being identified as HIV-positive. These include the risks of loss of health insurance (especially significant to a person entering a lengthy regimen of expensive treatment); loss of job or housing, and isolation from friends and relatives who may reject the individual known to be infected. Maintaining confidentiality about HIV status is difficult enough for a healthy person; it is much harder for a healthy person undergoing regular medical treatment.

Treatments will be costly. For example, if zidovudine were to be administered to an asymptomatic patient at half or full dosage currently prescribed for AIDS patients, the annual costs would be between $4,891 and $10,382.[22] Aerosolized pentamidine costs about $1,500 to $2,500 annually, plus the costs of the nebulizer and office visits.[23] Monitoring of T-cell counts, recommended at six-month intervals, costs $150. On the other hand, there would be savings in hospital costs for patients who did not get *Pneumocystis*. However, patients would still be vulnerable to other opportunistic infections requiring hospitalization. Furthermore, treatment for asymptomatic patients during the next few years will primarily involve experimental interventions or drugs, which are not covered by most private insurance companies or Medicaid programs. Many policies also do not fully reimburse the costs of drugs or treatment given in outpatient settings.

Finally, seropositive patients may have a very difficult time locating physicians willing to treat them. Few community physicians will care for AIDS patients, and there are even fewer willing to undertake still unproven therapeutic regimens for asymptomatic HIV-infected persons.

In sum, the benefit-risk calculus has many elements. Treatment for asymptomatic HIV infection is still evolving, costly, and with potential long-term risks. But AIDS is still ultimately a fatal disease, and early intervention offers both the potential of prolonging life and the psychological benefit of giving individuals a sense of control over their destinies. Given such uncertainty, patients, in consultation with their physicians, will weigh the various elements differently. Some will choose an aggressive, all-out approach; others will select certain treatments and not others; and some may prefer to watch and wait.

Justifications for and Limits of Screening for Early Intervention

In our ethical analysis, we draw on the principles of respect for persons, the harm principle, beneficence, and justice.[7] These four widely accepted ethical principles are derived from secular, religious, and constitutional traditions and are commonly applied to medicine, research, and public health.

Respect for persons requires that individuals be treated as autonomous agents who have the right to control their own destinies. Respect for persons requires that persons be given the opportunity to decide what will or will not happen to them. The right to privacy and the requirement of informed consent flow from this principle. A corollary—requiring persons with diminished autonomy to be given special protections—may also apply to some populations such as children and prisoners.

The *harm principle* permits limitations on an individual's liberty to pursue personal goals and choices when others will be harmed by those activities.

Beneficence requires that we act on behalf of the interests and welfare of others. The obligations of beneficence apply to actions affecting both individuals and the community. Potential risks must be weighed against potential benefits and the actions with the most favorable risk-to-benefit ratio adopted. The justification for public health authority derives from both the harm principle and beneficence.

Justice requires that the benefits and burdens of particular actions be distributed fairly. It also prohibits invidious discrimination.

These ethical principles may sometimes conflict. For example, the principle of beneficence and the harm principle may outweigh the need to obtain consent in some situations, but they never outweigh the obligation to treat persons with respect for their intrinsic worth and dignity. Considering both benefits and risks, and drawing on the ethical principles of autonomy, beneficence, and justice, we reach several conclusions:

1. ***There are now clinical and ethical grounds for establishing voluntary anonymous or confidential screening programs in settings where individuals who may have been infected with HIV are treated.***

Defining the populations for whom such routinely offered screening would represent a benefit will not be simple. Certainly those who report a history of high-risk sexual or drug-using behavior could benefit from early identification. On the other hand, some investigators have observed that self-reported behavior may fail to identify all those at increased risk for HIV infection.[24] Therefore, it will be necessary to recommend HIV testing to persons seen in clinical settings, such as STD (sexually transmitted disease) clinics where the level of HIV infection is high, and to others—pregnant women, for example—in geographic areas where there is an elevated level of infection.

Private physicians should discuss HIV testing with their patients and recommend it to those whose sexual or drug-using history reveals risk behaviors and those who are not sure about their past risks. Recommending testing to all adults, regardless of their history, as suggested by Rhame and Maki, would result in a massive diversion of resources with few benefits.

Adolescents who may be at high risk of HIV infection should also be offered counseling and testing. Adolescents at highest risk because of sexual or drug-using behavior are often alienated from their families. Ideally parents or another family member or trusted adult should be involved in the decision, both to provide emotional support for the adolescent and to facilitate therapeutic follow-up.

2. *Testing of competent adults for clinical purposes should be based on explicit informed consent.*

As the clinical justification for offering HIV testing increases, there will inevitably be a trend toward incorporating testing into the standard panel of "routine" tests. We use the term "routine" to mean that physicians should as a matter of good medical practice and beneficence initiate discussions about HIV antibody testing with their patients.[25] We reject any use of "routine" that involves testing first and talking about it later.[26] HIV testing should not be performed under the conditions of general or presumed consent that governs many others, but not all, medical tests. Presumed consent is an unwritten contract by which the patient, by supplying urine or allowing blood to be drawn, agrees to the routine testing of these materials. If the tests for HIV antibodies were not blood tests, but procedures that involved patient cooperation such as tests for colorectal cancer or mammograms, there would be no question that specific consent would be required. HIV infection is not like other clinical conditions, even those that are potentially lethal. It carries not only great psychological burdens but the possibility of severe stigma and discrimination, including rejection or avoidance by health care workers and poor-quality treatment.

The consent procedure preceding testing should carefully define the benefits and risks of testing. An honest appraisal of the situation enhances patient autonomy. When the possible benefits of testing are inflated, when the limited therapeutic possibilities are exaggerated, the difficulty of enrolling in clinical trials understated, or the fact that such trials may be placebo-controlled omitted from the discussion, the patient's right to an informed choice is undermined.

Some mothers, because of illness or drug addiction, may be unable to make decisions on testing for their children. However, many others are competent to do so. Competence is not a single standard; the determination in this case should focus on the specific question of decision-making for children, and not on other issues such as competence to make financial decisions or even decisions about the women's own health care. Mothers' consent for testing is critical since their involvement in monitoring the health status of their children will be especially important. In addition, newborn screening will also carry significant psychological and social consequences for mothers identified as infected. For some infants, who have no parent present or competent to give consent, there are significant barriers to testing, treatment, and enrollment in experimental protocols. These questions are beyond the scope of this article but should be addressed by policy-makers to find ways to both protect vulnerable infants and offer them whatever benefits exist for their conditions.

Individuals with diminished capacity to consent—those with mental illness or retardation, for example—should be considered on a case-by-case basis, with the involvement of guardians or other representatives. Here too the absence of a guardian may result in the denial of some kinds of care because of concern about the individual's competence to consent. Those with diminished capacity to consent should not be denied the benefits of potential therapeutic intervention. Procedures should be established to review individual cases of guardians' refusal to permit testing, or the absence of a guardian to give consent.

In the case of adolescents, clinicians will have to determine, again on a case-by-case basis, if an adolescent is mature enough to make the decision about testing, either alone or in consultation with a responsible adult. If so, parental consent ought not be required, even though it is clearly desirable. The notification of parents should be determined on a case-by-case basis, weighing the crucial role that they may be called upon to play in their children's health care against the possibility that they may harm the adolescent. There is no cure or effective treatment for HIV infection. Since long-term follow-up is required, with significant medical interventions, parental involvement is more essential than in STDs. In addition, very few teenagers will be able to pay for treatment on their own.

3. *There is no justification for mandatory screening on the grounds of therapeutic benefit.*

A. Competent adults—Mandatory (i.e., legally required or institutionally enforced) screening for early intervention for competent adults would be a major departure from the accepted standards of medical practice. In our legal and ethical systems, competent adults have the ultimate decision-making authority over their medical care. Despite the well-documented clinical benefits of screening for other potentially fatal diseases (breast cancer, for example) screening programs are entirely voluntary. Changing this standard because of the infectious and stigmatized nature of HIV disease would be a grave mistake.

The few situations in which mandatory screening for individual benefit occur (for example, screening for lead toxicity in the workplace) are narrowly construed and result in beneficial responses, such as offering affected persons different jobs without loss of salary or benefits. Even premarital syphilis screening, which many states have in recent years rescinded on grounds of cost-effectiveness, has as its primary goal the prevention of transmission, not the treatment of an affected individual. While many types of mandatory screening such as drug screening in some narrowly defined employment settings may be constitutional, their stated justification is the prevention of harm to others.[27] Proposals for mandatory HIV screening on clinical grounds do not fall into this category.

Because of the limitations of screening based on well-defined patient characteristics or community prevalence rates, the Centers for Disease Control recommended in 1988 that all pregnant women be "routinely" screened for hepatitis B surface antigen in order to initiate the available prophylactic treatment.[28] Such a universal, quasi-mandatory approach to screening pregnant women cannot be justified in the case of HIV.

If there were an intervention that both benefited an infected person and also prevented transmission by rendering him or her noninfectious, mandatory screening might be considered and might be justified on the basis of the harm principle. But even in that entirely hypothetical situation, the likelihood of public health benefit would have to be weighed against the possible side effects and the intrusive and long-term nature of the intervention. Since HIV is transmitted through behavior that can be modified, clinical intervention is not the only possible means of controlling the spread of infection.

Even those who acknowledge that mandatory screening is not justified for prevention of transmission, infection control, or therapeutic benefit might argue that the three purposes, when combined, may indeed create a justification. We reject such a claim. These three weak arguments do not make a strong one. It is ethically unacceptable to require or encourage testing on grounds of potential therapeutic advantage when in fact the purpose of screening is entirely different.

B. Newborns—The case of newborns presents a more complex situation. Infants cannot consent for themselves, and society has an obligation to assure that they are not deprived of potentially life-saving therapeutic benefits. Nevertheless, the welfare of children is assumed in general to be more effectively protected by deferring to parents. While respect for persons is usually considered to be a principle affecting individuals, family autonomy has a long legal and moral tradition as well.

Unlike the situation with competent adults, there are mandatory or quasi-mandatory newborn screening programs in place for a few conditions. Screening for phenylketonuria (PKU), for example, is mandated in most states. In the case of PKU, there is a definitive test to identify the rare infant with the genetic enzyme deficiency that prevents the metabolization of phenylalanine. There is a well-established therapeutic regimen—a diet low in phenylalanine—that is highly effective in preventing retardation. It must be initiated early in infancy and continued until the child is age 5 or older.

But even here there is controversy. Ruth Faden and others have argued that "there are cogent moral arguments against requirements of parental consent for PKU screening" and "compelling moral arguments against a policy of honoring parental refusals of PKU screening.[29] However, George Annas has asserted that *voluntary* screening for PKU can be equally effective and that the focus should be on improving the consent process and not on those few parents who withhold consent.[30]

In 1987, a National Institutes of Health consensus conference concluded that states should mandate the routine offering of sickle cell disease screening to newborns.[31] Sickle cell screening programs had been championed in the early 1970s but were beset by problems caused by the resulting stigmatization of those identified, the confusion between sickle cell disease and trait, and the absence of therapeutic interventions. The NIH consensus conference reviewed new evidence that prophylactic penicillin treatment of affected newborns prevented serious episodes of disease and, in some cases, death. Despite the clear potential benefits, the conference report called upon states to "mandate the availability of these services while permitting parental refusal." According to Dr. Marilyn Gastin of the National Institute of Health, at present about 20 states are implementing, or planning to implement, sickle cell newborn screening programs. Some of these allow parental refusal; many do not provide any mechanism to inform parents about their right to refuse.

Unlike the cases of PKU and sickle cell screening, however, there is at present no definitive screening test to identify the HIV-infected infant, no proven therapy, and no proven benefits to early intervention. There are also strong arguments *against* mandatory HIV screening at present. Mandatory screening of all newborns would entail the coercive identification of infected mothers, since the HIV antibodies in the infant reveal infection in the mother. These women are typically from minority communities. Often they are poor and have a history of drug use. They are particularly subject to attempts to override their parental rights. Unless specifically demonstrated to be unable to act in their child's best interests, mothers at high risk for HIV infection should have the power to exercise the rights accorded to other parents, including the right to refuse HIV testing for their infants.

Only when a definitive test that accurately identifies HIV-infected infants becomes available, and when a treatment has been demonstrated to be safe and effective in prolonging life and improving its quality for the child, will overriding parental refusal for HIV testing be ethically defensible on the basis of the harm principle. This position conforms to the conclusion of the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research that "programs requiring the performance of low-risk, minimally invasive procedures may be justified if voluntary testing would fail to prevent an avoidable, serious injury to people—such as children— who are unable to protect themselves."[32]

4. Mandatory named reporting of those diagnosed with HIV infection is unnecessary for clinical purposes and may be counterproductive.

The potential benefits that can follow from the early identification of infection has led some officials to reconsider their earlier opposition to the reporting by name of individuals with HIV infection to public health registries.[33] Such reporting, they have asserted, would permit careful follow-up and counseling regarding the importance of early clinical intervention and would facilitate partner notification to provide the same benefits to individuals reached through public health programs. In the first years of the AIDS epidemic the issue of reporting was the source of bitter controversy, especially in states with relatively low levels of HIV infection.[34] When the Institute of Medicine and the National Academy of Sciences considered the question in 1988 it declared that "although some arguments for mandatory reporting have merit . . . the costs far outweigh the benefits, especially if mandatory reporting discourages individuals from seeking voluntary testing."[35]

Now that the prospects for early clinical intervention are emerging and more people at risk are voluntarily seeking testing, it is especially critical to avoid public health measures that may foster anxiety about breaches of confidentiality. That is true regardless of the exemplary record of state health departments in maintaining the confidentiality of the records of those reported with AIDS and other diseases. To assure the proper counseling of HIV-infected individuals about the possibilities of early clinical intervention, it would be wiser to launch aggressive education campaigns targeted at both physicians and those at risk of infection. Partner notification is not dependent on named reporting. Counselors working with HIV-infected people should emphasize the importance of partner notification for clinical and public health reasons, and programs should be in place to assist in notification when the infected individual is unwilling or unable to do it personally.

5. *High-quality laboratory services must be used.* Beneficence requires that persons not be subjected to any risk—whether social, psychological, or medical—if the information about them to be generated in screening does not meet the current standard levels of accuracy. According to Lawrence Miike, testifying before a House subcommittee in October 1987,[36] studies by the Office of Technology Assessment have found extremely wide variability in laboratory performance. High-quality laboratory services will be essential not only for HIV antibody testing but also for T-cell monitoring, and as consideration is given to wider reliance on PCR techniques.

6. *HIV-infected individuals should be protected against discrimination.*

Fear of the discriminatory consequences of being labeled as HIV-infected continues to affect decisions regarding the willingness to be tested for clinical purposes.[37] Despite some advances of the past two years in providing statutory protections against the unconsented disclosure of HIV status, and in protecting the civil rights of infected individuals, patients must be informed that whatever benefits may currently flow from the early identification of HIV infection may be compromised by violations of confidentiality and acts of discrimination. This underscores the importance of the protection of the rights of HIV-infected persons, which should be enacted in federal law, as recommended by the Presidential Commission on the HIV Epidemic.[37]

7. *Screening programs to identify asymptomatic individuals for clinical purposes which do not at the same time plan for appropriate follow-up services fail to meet the ethical standards of justice or beneficence.*

The demands of justice go beyond a prohibition of discrimination. They require a systematic and full-scale commitment to planning for and providing the medical and social services that will be required to meet the needs of HIV-infected individuals.

With over 100,000 cases of CDC-defined AIDS reported in the US so far, one-third of them in the New York City-northern New Jersey region, the health care systems in heavily affected areas have been severely strained. Providing experimental and therapeutic regimens as well as careful monitoring for the estimated 1.5 million asymptomatic individuals with HIV infection will require a dramatic expansion of services.[38] If the majority of asymptomatic seropositive people were treated on the basis of the current Public Health Service recommendations, costs would run into the billions of dollars.

The need for such a commitment has been recognized by the Public Health Service as well as by some public health officials who are now pressing for more aggressive programs to identify individuals infected with HIV. Thus Dr. Stephen C. Joseph, Commissioner of Health for New York City, has stated, "[The] shift toward a disease control public health approach must be accompanied by ensured availability of needed clinical and social services."[33] But more than assertions will be necessary. The next phase of the epidemic will require a major infusion of public resources and a willingness to mobilize and organize the services that will so clearly be necessary.

Following the principles of justice and beneficence, the economic barriers that could restrict access to therapeutic agents that may retard the progress of HIV infection must be eliminated. This is an especially critical issue since so many of the infected are poor, uninsured, underinsured, and medically underserved. Only a last-minute intervention by Congress assured that individuals clinically eligible for zidovudine would continue to get it regardless of their ability to pay. But the willingness of the federal government to continue to fund such special AIDS-specific programs is not at all certain.

In its report on genetic screening and counseling, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research declared that "Screening programs should not be undertaken unless accurate results will be produced and a full range of prescreening and follow-up services are available."[39] That conclusion applies with equal force to screening for HIV infection. It is not ethically defensible to encourage individuals to undergo HIV testing for clinical purposes unless they will have access to available therapies regardless of ability to pay.

Some public health officials who acknowledge the critical shortage of affordable services nevertheless have objected to this conclusion. They have argued that only when individuals are identified through testing and begin to demand access to services will the resources be made available. Whatever the validity of such claims—and there is reason to doubt that the demands of the poor and disenfranchised would have such a desired impact in this case any more than they have had in the case of drug treatment and primary care—they are irrelevant from the perspective of this analysis. To encourage HIV testing for clinical benefit without informing individuals without insurance and primary health care that the necessary follow-up clinical services are virtually inaccessible would represent a breach of the principles that govern the process of informed consent. As Dr. June Osborn, dean of the University of Michigan School of Public Health, declared at the V International Conference on AIDS, "We must not use the cruelly false lure of access to inaccessible care to justify abandoning principles we have learned so dearly about the fundamental importance of confidentiality and human rights."

The challenge posed by AIDS is not unique: it simply underscores dramatically and urgently the importance of addressing the systemic failures of the American health care system, noted by every major organization and institution that has studied this question. Resolution of those problems is integral to any ethically justified clinical program of screening for HIV infection.

Conclusions

When HIV antibody testing first became available in mid-1985, its primary function was to prevent the spread of infection through the screening of blood, and, in conjunction with counseling, to foster behavior change. Out of the many sharp debates that surrounded the test at that time, a broad alliance of clinicians, public health officials, political leaders, and AIDS activists forged a consensus that emphasized the importance of specific informed consent for testing and the protection of the confidentiality of the test results. That consensus emerged in the context of relative therapeutic impotence.

Now that the clinical options for those with HIV infection have improved, and in light of the prospects for further advances, that consensus will be subject to challenge. The next phase of the HIV epidemic will thus be marked by improvements in therapies and by profound challenges to the ethical principles that should govern the practice of medicine and public health. Only if careful consideration is given to the rights of individuals, to respect for their privacy, and to society's obligations to provide the needed clinical and social services will it be possible to assure that the cautious optimism that is now medically justified will be translated into policies that are ethically justified.

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U. Michigan Receives $6 Million for New Geriatrics Center

The University of Michigan Medical Center has received a five-year $6.1 million grant from the National Institute on Aging (NIA) to establish a Geriatric Research and Training Center—the first of its kind in the United States. The grant will greatly enhance current research and training in geriatrics and aging. T. Franklin Williams, MD, director of NIA, said, "Today's serious shortage of geriatric educators and researchers is having a negative influence on our society's ability to provide quality care for older Americans." The NIA anticipates that there will be insufficient numbers of geriatric educators and researchers in the US to handle the volume of elderly patients expected by the year 2000.

The Institute of Medicine of the National Academy of Sciences estimates that the number of Americans older than 85—now 2.7 million—will double by the end of this century. At the present time, attending to medical needs of those age 65 and older (12 percent of the US population) accounts for one-third of a physician's time, 25 percent of medications, and 40 percent of acute hospital admissions. By the year 2000, short-term hospital use by older persons will rise 50 percent, and more than one million additional geriatrics will be receiving long-term health care. IOM called for establishment of Centers of Excellence in Geriatrics—such as the one at U-MI—to meet these needs.

THE IMPACT OF ROUTINE HTLV-III ANTIBODY TESTING ON PUBLIC HEALTH

National Institutes of Health
Consensus Development
Conference Statement

Volume 6 Number 5

Introduction

The appearance of acquired immune deficiency syndrome (AIDS) has brought suffering and death to those who are afflicted and, at the same time, has posed daunting challenges to those who care for the sufferers, to biomedical scientists, and to those responsible for public health and public policy. Among these challenges is the protection of the nation's blood supply from contamination by human immunodeficiency virus (HIV),* the causative agent of AIDS. This challenge was met rapidly by the development of laboratory tests to detect the presence of antibody against the virus. The application of these tests makes it possible to determine whether the person has been infected by the virus at some time and thus to exclude persons from donating blood or to discard blood already donated. In the past 15 months, the widespread application of these tests along with self-deferral and removal of HIV-positive subjects from the pool of donors has sharply reduced the likelihood of the virus being spread by way of blood products.

Remarkable progress has recently been made in isolating the virus and in developing reasonably reliable tests for detecting its presence in blood by measuring the formation of antibodies against it. Mobilization of the whole scientific community, from government agencies and industry to the individual investigator, has brought about this progress, boding well for the eventual prevention of the disease. In fact, the prevention of posttransfusion AIDS is a typical example of the gains to be achieved by many years of supporting basic research.

However, the introduction of these tests has brought with it some problems. Questions can be raised about interpretation of the tests and their extension to purposes other than protection of the blood supply. As with almost every aspect of AIDS, the facts, opinions, and uncertainties of science are rapidly translated into public beliefs and social policy. Often, this translation has been inaccurate and incorrect. Policy has been made, or recommended, on the basis of an assumed scientific certitude that in fact may not exist. Conversely, scientifically sound information has been ignored or distorted by policymakers. Scientists have often failed to communicate their findings in ways that are useful for public policy.

The tests for evidence of infected blood are not yet optimally effective. There is still room for improved applications of the scientific method to identify methods with increased sensitivity, specificity, and predictive value. Because no test can be totally devoid of error, there must be continuing vigorous efforts to educate the public about who is a suitable donor of blood and to facilitate anonymous self-deferral at the time of blood donation.

To enhance understanding among scientists, those responsible for the health of individuals and of society, and the public at large, the National Heart, Lung, and Blood Institute of the National Institutes of Health (NIH) and the NIH Office of Medical Applications of Research sponsored this Consensus Development Conference on the Impact of Routine HIV-Antibody Testing of Blood and Plasma Donors on Public Health. Other sponsors of the conference were the Centers for Disease Control; the Food and Drug Administration; the Clinical Center.

The National Institutes of Health urges that this summary statement be posted, duplicated, and distributed to interested staff.

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*Previously referred to as HTLV-III/LAV, and subsequently referred to in this document as HIV in accordance with emerging and recommended usage.

NIH: the National Institute of Allergy and Infectious Diseases, NIH; and the National Institute of Mental Health.

The conference brought together biomedical investigators, blood bank specialists, clinicians, consumers, and representatives of public interest groups. Following 2 days of presentations by medical experts and discussion by the audience, the consensus panel worked hard to interpret the scientific evidence. Comments and recommendations are organized according to the following questions:

- What tests are currently being used? What are their performance characteristics?
- What constitutes a positive test? How should a positive HIV-antibody test result be interpreted? How should these tests be used?
- How should positive test results be handled?
- What are the psychosocial ramifications for blood donors of knowledge of a positive test result?
- What impact has testing had on transfusion medicine?
- What research directions should be pursued?

1.

What tests are currently being used? What are their performance characteristics?

There are three approaches to detecting HIV infection. Listed in decreasing order of difficulty and expense, these are:

1. Detection of the virus by culturing it.
2. Detection of antigens elaborated by the virus and present in blood.
3. Detection of HIV-specific antibodies that are produced by the infected person's immune system.

Two tests mainly support the entire current testing program. Both are of the third type. ELISA (enzyme-linked immunosorbent assay) reacts to the presence of antibodies in the donor's blood, showing a more intense color as larger quantities of the antibodies are present in the serum. A positive reaction is recorded where the observed intensity exceeds a cutoff value set by the manufacturer of the test kit. If the cutoff value is set low, so that relatively faint specimens are recorded as positive, the chance of detecting HIV cases with low levels of antibody are increased. At the same time, such a low threshold increases the chance of recording as positive samples that do not contain antibodies against HIV which can also produce color in the system. To protect the blood supply, it is prudent for a given test to set the threshold low, and accept the increase in false positives that must accompany that low threshold.

With a low threshold the ELISA test is quite sensitive; that is, truly infected persons are highly likely to give a positive reaction. But, uninfected persons—who are vastly more numerous—also occasionally give positive reactions to this test. This small fraction of uninfected donors produces many more of the positive reactions than arise from positive reactions of the few persons actually HIV-infected. That is, the odds are great that any single ELISA-positive reading comes from an uninfected person. Furthermore, low positive values are often not reproducible; that is, a repeated, independent sample from a donor whose first test was barely positive will likely turn up negative.

Current practice is that all donors are ELISA-tested. If the test is negative the unit of blood is acceptable. If there is a positive reaction, two further ELISA tests are performed on the same unit. If both are negative, the unit is acceptable. If either is positive, the unit is classified as "repeatably reactive" and is destroyed.

In the nonprofit blood banking system, there is further testing of the blood of a repeat reactor, aimed at clarifying the person's HIV status, which is still ambiguous since so many HIV false positives occur among the ELISA repeat reactors. The Western blot test is then applied. It, too, is an antibody detecting test, but it differs from the ELISA in several ways:

1. It gives information about particular antibodies among the several that HIV antigens may elicit; prominent among these are antibodies against p24 and gp41.
2. It uses electrophoresis and is thus more expensive and demanding of expertise than the ELISA.
3. It is less likely to give a false positive or false negative result.

If the specimen is Western-blot-positive, the donor is regarded as infected with HIV and notification of the donor is attempted. If the repeat reactor's Western blot test is negative, the donor may be informed that:

1. The blood is not, and will not be usable.
2. The donor in all probability is not infected.

To protect the quality of the blood supply, it is essential to reduce the number of false negatives to a minimum. However, false negatives cannot be totally eliminated because some sera contain too little anti-HIV antibody to be detected; they come primarily from donors who have been infected very recently, typically during the first 6 weeks of infection, or from individuals who for one reason or another form antibody very slowly. It is essential to increase the sensitivity of methods for detecting anti-HIV-antibody and to develop methods to detect and measure HIV antigens or infected T_4 cells.

Several versions of the ELISA test are on the market. They differ in their comparative sensitivity to the various antigens of HIV, and thus reflect somewhat different information about the antibodies in a given blood sample. They also presumably differ in sensitivity to sample constituents responsible for false positives. The cost-benefit ratio of simultaneously using ELISA tests from two different manufacturers on each sample to improve accuracy should be explored.

Several other methods of detecting anti-HIV antibodies are very useful for confirming and extending results obtained by the ELISA method, but are more time-consuming. Western blotting is difficult to standardize, but staining of p24 together with gp41 is unequivocally positive. Correlation with intermediate and high ELISA values is excellent. Radioimmune precipitation (RIP) and radioimmune assay (RIA) can be made both sensitive and specific by using very highly labeled antigens, but require skilled personnel and involve the use of radioactivity. HIV isolation is very difficult, time-consuming, and requires highly skilled personnel; it does not lend itself to analysis of large numbers of samples. It correlates highly with high ELISA values.

The most promising new approaches will be the development of fluorescent antibody (FA) techniques for detecting infected T_4 lymphocytes and the development of techniques for detecting viral proteins, based either on antigen capture or on reverse transcriptase (RT) activation and synthesis of HIV DNA, which can then be detected with high sensitivity and specificity.

2.

What constitutes a positive test? How should a positive HIV-antibody test result be interpreted? How should these tests be used?

The virus thought to cause AIDS has been isolated and its genome and gene products are largely characterized. Tests have been developed for the detection of virus, virus-coded proteins, and antibodies directed against those proteins. These developments have facilitated large-scale screening of blood and blood products for viral antibodies. Clearly, the tests in use have enhanced the safety of transfusion procedures.

Current procedures utilize an ELISA test for detecting antibodies against HIV as an initial screen. An additional test, the Western blot, is used to test sera found repeatably reactive in the ELISA test. Extensive experience has demonstrated that many sera that are repeatably reactive in the ELISA test do not react when tested by Western blot analysis. These discordant results indicate that many of the sera that are repeatably reactive in the ELISA test do not represent combinations with virus-specific proteins and often may not indicate the presence of an HIV infection.

Resolution of this problem is difficult because of limitations in currently available information. This is partly because investigators often use different methodologies, and licensed tests from different manufacturers probably differ in subtle yet possibly important ways. There are few published comparative analyses of the tests used in the field. Further, Western blots have generally been carried out by personnel who are aware of the fact that the sera they are testing have reacted in the ELISA test. In addition, it often is not possible to estimate the specificity of these tests because ELISA-negative sera are not being routinely tested by Western blot. Consequently, there is still a need for rigorous studies to clarify many issues regarding interpretation of test results.

The most specific test for infectivity remains virus isolation; however, because of the complexity and difficulty of isolating HIV in cell culture, this is an impractical method for large-scale use. Some form of the ELISA test with enhanced sensitivity and specificity remains the most practical and feasible procedure for large-scale screening of the blood supply. Improved confirmatory methods should be developed that can be used in conjunction with such a test. Even with currently available tests, however, it is essential that confirmatory studies be performed without the laboratory personnel knowing the prior ELISA results. Specimens should be identified by a code number only and a suitable number of ELISA-negative specimens should be included in each test run.

For the purposes of notifying the donor, a confirmatory test such as the Western blot should be applied to resolve the actual HIV status because the repeated reaction may be caused by factors such as autoimmune or cell-line-specific antibodies. Currently, however, blood banks are obliged to exclude sera that test repeatably reactive in the ELISA regardless of any confirmatory test results. Many of these almost certainly represent false positive reactions. It is unfortunate that a considerable number of donors are functionally excluded from donation because of their questionable test status. Efforts should therefore be made to find ways to identify ELISA-positive individuals who are not infected so that their true serological status may be defined and their return to the blood donor pool expedited.

Available data indicate that the presence of virus precursors or antibodies in the blood reflects the continuing presence of HIV in the host. Thus, detection of such components represents a sign of continued infectivity of the blood. Like many other chronic viral infections, the period very shortly after exposure is often likely to be characterized by lack of antibody and by levels of virus proteins below the threshold of detection. In addition, biologic variation of both host and pathogen suggest that some chronically infected individuals do not synthesize virus-specific antibodies or make quantities of viral proteins that can be detected by assays currently in use. Nevertheless, such individuals are potentially infectious. Thus, while total elimination of infected blood from the national supply is not immediately feasible, it remains a desirable goal.

3.

How should positive test results be handled?

A positive test* has the following significance as currently understood:

1. Such persons are infected with HIV.
2. Most persons infected with retroviruses such as HIV are infected for life.
3. All persons who are antibody-positive for HIV, whether they are symptom-free or ill, must be considered to be potentially infectious to others by sexual transmission, by sharing of drug injection equipment, by childbearing, or by donation of blood, semen, or organs.
4. Antibody positivity is not synonymous with having AIDS. However, by current estimate, as many as 35 percent of HIV-antibody-positive persons may experience progression to AIDS over 6 to 8 years.
5. We cannot precisely predict who among persons with antibody positivity will be ill or fatally ill in the future and it is not possible at present to prevent such outcomes.
6. All antibody-positive persons should seek information and advice on how to protect their sexual contacts and future children from infection.

The panel believes that there is a clear ethical responsibility on the part of blood- and plasma-collection centers to notify individuals with repeatably reactive blood in a sensitive, humane, and supportive manner. Consideration should be given to the donor's cultural and linguistic background. The need to maintain confidentiality of the information creates a duty on the part of blood-collection centers to assume primary responsibility for notifying positive donors of their test results.

Notification of donors serves two purposes:

1. It contributes to controlling the spread of HIV by encouraging self-deferral and changes in sexual practices
2. It provides circumstances for optimizing the health and well-being of the affected individual.

Differences exist across communities with respect to the process by which notification is accomplished. the nature of the information provided, and the extent of counseling that is provided. The panel does not believe that any single approach would be universally applicable.

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*Positive: describes a repeatably reactive sample which is determined to contain antibody by an additional specific test, such as Western blot, radioimmunoprecipitation, and the like. Persons who have positive sera are termed "seropositive."

Notification should be followed by education. The panel believes that he central component to education . person-to-person interchange between the donor and the counselor. Additional techniques as videotape presentations and ed materials may supplement, but not substitute for, personal interchange. Appropriate elements of a supportive counseling program for persons who are seropositive include education about the natural history of HIV infection and the meaning of a positive test, advice on behavioral changes that will protect one's sexual partner(s) from infection, and referral to additional resources.

While blood collection centers will rarely have the trained personnel or assets to provide extensive and specialized counsel, we believe that they have a duty to cooperate with community agencies that can ovide the necessary supportive ervices and to make effective referrals. These referrals would include the person's physician and r long-term counseling services, d such community agencies as local health departments, alternate test sites, AIDS service organizations, social service agencies, and others.

Confidentiality should be carefully and strictly maintained due to the sensitive nature of the information. Test results should be released to parties other than the patient only when there is a scientifically valid and legitimate need to know for public health purposes and, in principle, with the patient's specific consent.

Current practice in many centers is to enter the names of persons hose blood is repeatably reactive ut negative by Western blot into lists of deferred donors. We believe that it is inappropriate to enter a on's identity into such a list without his knowledge and without giving him the personal advantage of sharing that knowledge and its meaning. It is common practice to allow such individuals to donate again, but to discard their blood without their knowledge. This practice should not continue; these donors have a right to be advised of their status.

Blood-collection agencies currently maintain lists of deferred donors onto which are entered the names of HIV-antibody-positive donors. The agencies believe that such lists increase the likelihood that infectious units of blood will be screened out in the future should positive donors not self-defer. On the other hand, such lists are a potential source of loss of confidentiality for donors should their identity be inadvertently revealed. We believe that a balance of interests supports the entry of the names of those who are believed to be truly positive or whose status cannot be satisfactorily resolved but only if such donors are informed initially that their name will be listed, if the list is very securely held, and the list is used only for the limited purpose of protecting the quality of the blood supply. The actual utility of such lists should be regularly evaluated as technology improves.

Persons found to be seropositive may have a history of previous blood donations. For such persons, the question then arises about their past donations that have already been transfused into patients. In these cases, the blood bank has a serious responsibility to notify the hospital to which that blood was sent. It is the responsibility of the hospital, directly or through the patient's physician, to notify the patients of the possibility of having received seropositive blood and to educate them about the meaning of this. It is our opinion that, while the blood banks do not have the primary responsibility for the notification and counseling of recipients, they should, within their means, assist hospitals and physicians with accurate and effective information.

The repeatably reactive donors (by ELISA) in the plasmapheresis setting cannot be characterized without additional testing as being either positive or negative for anti-HIV-antibody. If the plasmapheresis industry is unwilling to test these donors further, the situation should be explained to the donor and the donor should be referred to an agency where such testing and pretest and posttest counseling are available.

4.

What are the psychosocial ramifications for blood donors of knowledge of a positive test result?

Everyone involved in blood and plasma collecting is aware of the potential psychosocial ramifications of the knowledge of a positive test result. Nevertheless, current data do not reveal the magnitude and nature of the short- and long-term psychosocial adjustment problems that seropositive donors and their sexual partners and family members experience. Possible outcomes include the effects on the individual's psychological and physical health, subsequent sexual behavior, lack of self-deferral behavior, and functioning in one's work and other social roles. Other research concerned with risk factors in health and illness has suggested that these outcomes will vary with the social and political climate of the community, the sociodemographic characteristics of the subpopulations at risk, the individual's personality traits, social support system, and characteristic mode of coping.

Due to issues of confidentiality, the education and initial notification of donors of confirmed reactive and positive tests is the responsibility of plasma- and blood-collecting institutions and begins prior to blood donation. Anticipation of the donor's fear and distress is not a valid basis for not informing the donor. The content and manner in which the message is delivered may play a role in modifying the stress of being informed subsequent to a positive test result. In the notification procedure it is critical to differentiate between the ELISA test defined as repeatably reactive, and the individual defined as seropositive based on additional confirmatory tests. It is also the responsibility of these centers to offer followup support and counseling through referral to the health care system.

There is a need for rigorous psychosocial research that will provide such data necessary to determine behavioral outcomes and to design and evaluate appropriate intervention strategies. The literature on the psychosocial outcomes of other life-threatening chronic conditions should be useful in this endeavor and will enhance research concerned with psychosocial ramifications for blood donors with positive tests.

5.

What impact has testing had on transfusion medicine?

HIV testing has important implications for blood donors, patients, practicing physicians, blood banking operations, and manufacturers of blood products and devices.

Donors

The panel unanimously affirms that the primary means of preventing AIDS and protecting the public health is through the responsible behavior of individuals. Thus, the primary public health measure is education regarding what constitutes risky behavior and ways in which such behavior might be modified. With regard to safety of the blood supply, this responsible behavior consists of persons who are likely to be infected refraining from blood donation. This behavior must be encouraged in every reasonable way. It is our belief that punitive and threatening measures against groups that are at increased risk are counterproductive; they drive individuals away from responsible behavior and make education almost impossible.

Voluntary blood donors have the right to expect confidentiality of records of blood donation and anonymity with respect to the recipient of their blood. They should receive an explanation of tests to be performed, consequences of a positive test, and details of any lists on which their name may be entered.

Two widespread misconceptions regarding HIV infection exist among potential donors. The idea that blood donation places a donor at risk for AIDS is patently false. It is also incorrect that all infected donors will be detected by screening tests. Informational programs to dispel these ideas are needed.

Because of real or perceived social pressures, some persons at risk to transmit HIV may feel compelled to donate blood. Procedures should be adopted by all blood banks to allow donors to indicate confidentially that their blood should not be transfused (self-deferral). Persons at risk for AIDS should be advised through programs of public education not to donate blood.

Alternative test sites should be available to allow anonymous access to testing without the need for voluntary blood donation.

Practicing Physicians

Blood utilization in the United States has declined significantly since 1982 the first such change in more than three decades. Much of this reduction appears to be the result of more judicious use of blood transfusion therapy by physicians. Preoperative autologous blood donation and intraoperative blood salvage have increased significantly and should be encouraged. These developments have reduced patient exposure to homologous blood and reflect good transfusion practice. Efforts should be made to increase the knowledge of practicing physicians about transfusion medicine and to make consultation readily available to them. Recipients should be adequately informed about the risks of blood transfusion. Effective peer review of transfusion practices should be maintained, and recording of the indications for blood transfusion in patient charts should be encouraged. All possible steps should be taken to avoid unnecessary blood transfusion. This is especially critical for neonates, who may be uniquely susceptible to HIV infection.

Blood Banks

There is uniform agreement that autologous blood is the safest form of transfusion therapy. Blood banks and blood centers should make this option available to all qualified healthy people with a scheduled elective operation, simplify the donation process to the extent possible, and inform physicians and patients about the advantages and mechanics of this approach. However, stockpiling of autologous blood without an imminent need should not be countenanced. In some areas, blood banks and blood centers [illegible] acceded to requests by individual patients for "directed donations," that is, donations by persons known to the prospective recipients.

lthough no evidence was presented to show that directed donations are ny more or any less safe than nations from the general public individual patients, the panel ard persuasive arguments against directed donations based on social and ethical considerations.

Transfusion medicine is emerging as a sophisticated individual discipline. Additional physicians well-trained in this specialty are needed to meet educational needs, assure appropriate transfusion practices, and encourage research and training programs.

Impact on Manufacturers of Blood Products and Devices

The plasma fractionation industry uses large pools of plasma for the preparation of certain lots of clotting factor concentrates. Despite highly sensitive tests for anti-HIV ntibody used to screen individual s of plasma, final products may ain infected units not detected by these assays. Reasonably successful methods have been developed to inactivate virus in these products. Recent reports of HIV seroconversion in previously seronegative hemophiliacs receiving heat-treated factor VIII concentrates suggest the need to develop better procedures for removal or inactivation of virus. Production of certain clotting factors by recombinant DNA techniques and by monoclonal antibody methods is now in progress and should be encouraged.

Devices have been developed to salvage patients' blood during operations, following trauma, and in other selected conditions. Recognizing the advantages of autologous lood, the panel recommends that dustry continue to improve blood ge devices.

6.

What research directions should be pursued?

It is remarkable that in the few years since AIDS was recognized, the human immunodeficiency virus has been characterized and tests for specific antibody have been developed and implemented for the protection of blood donors and transfusion recipients. However, the ELISA screening tests in current use fail to detect some infectious donors and yield positive reactions with many donors who are HIV-negative. It is essential that more sensitive tests be developed to detect low levels of antibody. Highly specific confirmatory tests capable of distinguishing false positive from true positive reaction and that can be performed in a blood center are also required. In the early stage of HIV infection, virus may be present without antibody. In rare individuals with infection of longer duration, antibody levels may be too low to be detected with any test. Highly specific methods for detecting HIV in donor blood are available, but these are time-consuming, expensive, and lacking in sensitivity. Since direct detection of virus offers the most specific way of identifying donors who carry HIV, emphasis should be placed on the development of improved methods for detecting the HIV genome and virus-specific proteins in blood samples.

No definitive measures are yet available to predict which persons infected with HIV will develop AIDS, and much remains to be learned about modes of infection and the best ways of preventing the spread of HIV to personal contacts. Longitudinal studies of seropositive persons are needed to define outcomes in these individuals. Even in the absence of a cure for AIDS, better information on these issues would be invaluable to blood transfusion recipients and those carrying HIV.

AIDS presents enormous challenges for psychosocial research. Persons in high-risk groups must be informed about the danger of transmitting HIV by transfusion and persuaded to comply with blood donor regulations. Effective methods of counsel and support for HIV-positive persons should be characterized and implemented. Considering that the next great threat from AIDS may come from heterosexual spread, means should be found to educate young, sexually active persons about the hazard of AIDS and the changes in behavior required to reduce the risk of contracting or transmitting this disease.

Since no methods of donor screening are likely to eliminate all risk of HIV transmission by blood, better methods of inactivating or removing HIV from blood products, especially those produced from plasma pooled from many donors, should be sought. Production of such products by recombinant DNA methods eventually should eliminate the risk of transmitting HIV and other infections with them.

Finally, and most obviously, the extensive efforts now under way to develop effective therapeutic agents for AIDS and methods for immunization against HIV should be sustained until these goals are achieved.

Conclusions

Remarkable progress has been made in applying the fruits of basic research to the development and

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detection of antibodies against HIV in blood collected for transfusion. Although test sensitivity is constantly improving, there is never a perfect test and exclusion of possible infected donors remains important. A procedure should be adopted by all blood banks to allow donors to indicate confidentially that their blood should not be transfused (self-deferral).

As a result of the policy of minimizing the chances of positive blood slipping through the screen, false positive tests will always occur. Extra efforts will be required to reassure donors and to salvage blood now discarded because of a false positive reaction.

Confirmed positive tests mean that the donor is infected and has an unknown but real chance of developing AIDS. Disease will continue to be recognized in those who received infected blood before universal testing began and in the rare instance of transfusion of a blood product that for whatever reason falsely tested negative.

A policy of protection of the individual donor's privacy should be vigorously pursued; however, blood banks must be responsible for properly informing the individual and arranging for counseling. Much needs to be learned about the short- and long-term psychosocial adjustment problems of healthy people who are told they have an infection that may prove life-threatening.

Every aspect of the problem requires continuing research. More sensitive tests that more specifically identify infectivity must be developed and tested in epidemiologically sound ways. Better methods of discouraging possibly infected donors and handling the psychological problems occurring in those with positive tests must be discovered through sound research projects.

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CRISIS INTERVENTION TECHNIQUES

- Relieve Isolation
- Remove Lethal Weapons
- Encourage Alternate Expression of Anger
- Avoid Final Decision of Suicide During Crisis
- Re-establish Social Ties
- Relieve Extreme Anxiety and Sleep Loss

ABC of AIDS

DAVID MILLER

COUNSELLING

Education
  Safe sex
  Public ignorance

Support
  Individual counselling to prevent psychological morbidity

AIDS counselling has two main aims.

The first is to educate sexually active people to avoid and stop the spread of the human immunodeficiency virus (HIV). Counselling and health education of individuals is the only demonstrably effective means of motivating reliable changes in sexual behaviour.

The second aim is to prevent and manage the psychological morbidity arising from fear of and knowledge of HIV infection. Again, an individual's fear of HIV infection is reliably managed only by individual counselling. When counselling is not provided or is insufficient severe, chronic psychological or psychiatric disturbance may result. Suicides have occurred, for example, where counselling services have been absent.

These two aims—education and support—are necessary because the acquired immune deficiency syndrome (AIDS) can so easily be prevented by changes in sexual behaviour and because the stigma associated with AIDS can lead to overwhelming fears of rejection and oppression. The public's ignorance of the true nature of HIV infection, routes of transmission, and consequences means also that the test for HIV antibodies is widely misunderstood. Counselling therefore has an important part to play well before knowledge of infection is reliably determined with the antibody test.

When is counselling necessary?

Before an HIV test
  Sexual history and assessment of likely risk
  Information and advice

After the test and diagnosis
  Counselling and support
  Follow up of patient and partner
  Referral to other agencies:
    Terrence Higgins Trust
    Body Positive
    The Samaritans

There are two stages at which counselling is necessary: before blood is taken for antibody testing and when a patient is found to be seropositive.

Pretest counselling requires a discussion about the meaning and potential consequences of the test. Preparation for the possibility of a positive result (if the sexual, drug use, or other history indicates) is essential in helping to minimise adverse psychosocial consequences if the result is indeed positive.

A necessary component of precounselling is therefore a thorough sexual history, so that the counsellor can gain a clear understanding of the likelihood of infection. The specifics of the sexual history will obviously have a considerable bearing on the need for antibody testing.

When a patient is found to be seropositive or diagnosed as having symptoms of HIV disease the period immediately afterwards will usually be characterised by shock, acute anxiety, depression, often impulsive despair, and social trauma. The alert doctor will ensure that community support is on hand to cushion the patient at this highly vulnerable time. Patients invariably perceive a diagnosis of HIV infection or seropositivity as life threatening, and their normal psychosocial responses may, if unattended, lead to serious practical and emotional consequences, especially if the social confidentiality of the patient is not strictly preserved and continued access to counselling is denied.

Counselling before HIV testing

The test

Is not a test for AIDS
Necessitates sufficient time elapsed for seroconversion to have occurred
Indicates only previous exposure to HIV
Gives no indication of prognosis, severity of infection, or infectiousness

Practical consequences of being identified seropositive

Ineligible for future life insurance or some mortgages
Possible difficulties obtaining dental and medical treatment
Precluded from some types of employment and employer
Dismissal by some employers with resulting financial burd

Potential psychological consequences of being seropositive

Unresolvable uncertainty
High level anxiety, depression, guilt, and obsessive disorders
Relationship implications

Other issues

All persons potentially at risk should adopt safer sex and risk reduction guidelines

Themes in counselling

AIDS anxiety

With the advent of government health education and media coverage many people present voicing fears about their possible exposure to infection. These fears often show a misunderstanding of the routes of HIV infection or of true seroprevalence at the time they feared they might have been exposed.

Anxieties within this group commonly relate to non-sexual modes of spread, such as shared toothbrushes, cooking and eating utensils, towels and linen, and bathrooms and non-sexual touching and kissing. People worried about such contact usually respond positively to clear, rational discussion of the known routes of infection and the absence of risk associated with such activities.

The worried well

The worried well are more difficult to manage. Patients in this group present with multiple physical complaints, which they interpret as sure evidence of their HIV infection. This occurs despite often repeated assurances that, on the basis of their sexual history, they could not (or would be extremely unlikely to) have come in contact with HIV. Typically, fears of infection reach obsessive proportions, and frank obsessive states are often seen. HIV seems to act as a vehicle for the expression of their psychological vulnerability and sexual guilt.

This group shows a variety of characteristic features (see box), including a low risk sexual history, social isolation, multiple misinterpreted somatic features, a high level of medical consultation, and high levels of anxiety. These patients are rarely reassured for more than a brief period after clinical or laboratory confirmation of the absence of HIV infection. They represent a major drain on counselling resources, and further referral for behavioural psychotherapy or psychiatric intervention is often indicated.

People positive for HIV

Themes that arise during counselling of people positive for HIV—whether they have symptoms or not—often mimic the crisis responses to life threatening news seen in patients with cancer but with the added pressures of social stigma and the threat of social oppression. Effective management requires allowing time for the shock of the news to sink in; there may be a period of emotional "ventilation," including crying and hysterical speech. The counsellor should provide an absolute assurance of strict confidentiality and rehearse the solutions to practical problems such as who to tell, what needs to be said, the involvement of loved ones, access to medical and dental practitioners, future sexual options, and financial and legal management. When patients are diagnosed with HIV disease counselling will also include discussion of possible treatment regimens and usually the question of prognoses. It is important to avoid the trap of attempting definitive estimates of life expectancy, which may encourage chronic depression and undermine the patient's motivation and compliance.

Characteristics of the worried well

- Low risk sexual history
  — including covert and guilt inducing sexual activity
- Poor postadolescent sexual adjustment
- Social isolation
- Dependence in close relationships (if any)
- Multiple misinterpreted somatic features
  — usually associated with undiagnosed viral or postviral states (not HIV) or anxiety or depression
- Psychiatric history or a high level of consultation with general practitioners or physicians
- High levels of anxiety, depression, and obsessional disturbance
- Increased potential for suicidal activity
- Repeated negative HIV tests

SAFER SEX
DON'T DREAM IT
DO IT!
HIGGINS
AIDS
and
AIDS
MORE FACTS FOR GAY MEN
WOMEN
AND
AIDS
TERRENCE HIGGINS TRUST
Facts about
drug users

Psychological issues in HIV/AIDS counselling

Shock:
- of diagnosis and possible death
- over loss of hopes for good news

Fear and anxiety:
- uncertain prognosis and course of illness
- of disfigurement and disability
- effects of medication and treatment
- of isolation and abandonment and social/sexual rejection
- of infecting others and being infected by them
- of lover's ability to cope and their possible illness
- of loss of cognitive, physical, social, and work abilities

Depression:
- over "inevitability" of physical decline
- over absence of a cure
- over the virus controlling future life
- over limits imposed by ill health, and possible social, occupational, emotional, and sexual rejection
- from self blame and recrimination for being vulnerable to infection in the first place

Anger and frustration:
- over inability to overcome the virus
- over new and involuntary health/lifestyle restrictions
- at being "caught out" and the uncertainty of the future

Guilt:
- over past "misdemeanours" resulting in illness "punishment"
- over possibly having spread infection to others
- over being homosexual or a drug user

Obsessive disorders:
- relentless searching for new diagnostic evidence on body
- faddism over health and diets
- preoccupations with death and decline, and avoidance of new infections

AIDS: Safer sex guidelines

No risk
- Solo masturbation
- Massage away from the genital area

Medium risk
- Wet kissing
- Fellatio (sucking) may be safe if you stop before climax
- Urination (water sports) external only
- Anilingus (rimming)

Low risk
- Mutual masturbation
- Dry kissing
- Body rubbing

High risk
- Anal and vaginal sex may be safe if a condom is used
- Fisting (insertion of hand or fist into rectum)
- Sharing sex toys and needles
- Any sex act that draws blood

Risk increases with multiple partners

With all seropositive patients it is crucial to provide a "lifeline" for the first few days (telephone numbers of the clinic, community agencies concerned with HIV, the Samaritans) and, if possible, to ensure that they will not be left alone during this time (when suicidal impulsiveness or a catastrophic reaction is most likely). Likewise, patients should be advised against telling at this stage their result or diagnosis to others who are unaware of their attendance at the clinic. The reactions of others (especially employers) are quite unpredictable and may lead to adverse consequences. Once the patient has calmed down an appointment should be made to see him or her again, perhaps in the company of a lover, spouse, relative, or parent, within five days.

At the follow up session issues relating to safer sex; domestic, occupational, and recreational infection control; "health boosting" (healthy eating, drinking, sleep regimens, etc); and who should be told and how to tell them can be repeated. A partner can be involved only with the consent of the patient, but it is important for the following reasons:

(1) Adjustments in sexual behaviour can be discussed and explained clearly to both.

(2) Standards of hygiene can be clearly explained—for example, what to do after spillages of body fluid in the home.

(3) Misconceptions about HIV transmission or infectiousness can be removed.

(4) The partner's and the patient's psychological responses to the diagnosis or results, such as anxiety, depression, obsessional states, can be explained and placed in a manageable perspective.

(5) The partner can be enlisted to help with the effective monitoring and management of the patient's condition.

Partners (and family members) often have higher and more chronic levels of psychological morbidity arising from knowledge of HIV infection in the patient than the patients themselves. Continuing support is often required to manage this, particularly as difficulties in the relationship that are not attended to (including role changes and fears about both partners being infected) will lead in many cases to a breakdown of the partnership, leaving the patient more acutely vulnerable.

In many cases follow up counselling will need only two or three sessions. The number of sessions largely depends on the physical health of the patient and the nature of his or her psychological response to infection. At follow up meetings it is important gently to screen for any indications of psychological or psychiatric vulnerability. The presenting themes seen in the worried well are a good indication of vulnerability in all patient groups.

Linking with community and statutory agencies

HIV and AIDS counselling could not succeed without active liaison with established community advice and support agencies such as the Terrence Higgins Trust or social services agencies responsible for home help and housing. Such services provide much required support and back up counselling for both inpatients and outpatients. Links with these services should be planned as an integral part of any HIV/AIDS counselling initiative from the outset. Such links must be kept open and flexible to ensure that medical information and advice are consistent across all levels of intervention and to enable new crises to be managed effectively as they arise.

Counselling qualifications

Effective counselling requires the following qualifications.

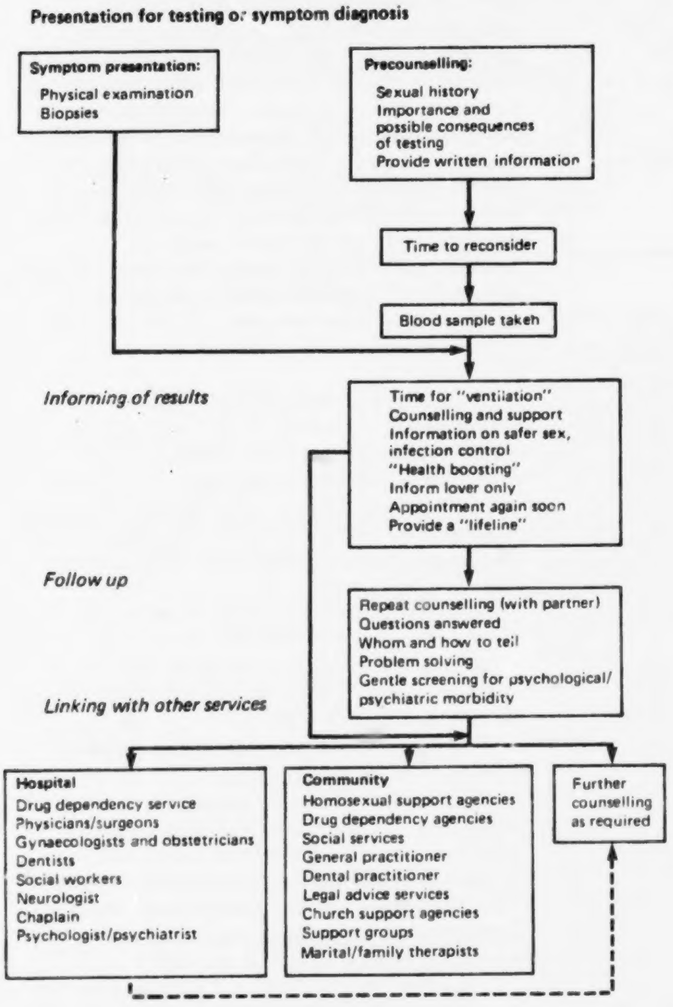
(1) A thorough working knowledge of HIV and its clinical manifestations and an ability to keep up with developments in treatment and diagnosis in this rapidly changing subject.

(2) A working knowledge of the lifestyles of patient groups and an ability to discuss tactfully issues of patient sexuality and lifestyle.

(3) A working knowledge of the range of "backup" services available for patients with HIV infection and AIDS together with an ability to communicate effectively, tactfully, and sympathetically with people from a wide variety of backgrounds and lifestyles (medical and non-medical).

(4) The ability to recognise common psychosocial and clinical complications arising from HIV infection, including anxiety, depression, obsessive disorders, neurological indications, and suicidal risk. If counsellors cannot manage such issues themselves they must be able to recognise when to refer patients elsewhere.

Possessing relevant information, skills, and interest is often a more useful prerequisite than possessing formal counselling qualifications or belonging to a particular profession. Because counselling opportunities and needs so frequently arise in the context of general practice, establishing the availability of counsellors or the learning of such skills is an important requirement for the forseeable future.


Presentation for testing or symptom diagnosis
Symptom presentation:
Physical examination
Biopsies
Precounselling:
Sexual history
Importance and possible consequences of testing
Provide written information
Time to reconsider
Blood sample taken
Informing of results
Time for "ventilation"
Counselling and support
Information on safer sex, infection control
"Health boosting"
Inform lover only
Appointment again soon
Provide a "lifeline"
Follow up
Repeat counselling (with partner)
Questions answered
Whom and how to tell
Problem solving
Gentle screening for psychological/psychiatric morbidity
Linking with other services
Hospital
Drug dependency service
Physicians/surgeons
Gynaecologists and obstetricians
Dentists
Social workers
Neurologist
Chaplain
Psychologist/psychiatrist
Community
Homosexual support agencies
Drug dependency agencies
Social services
General practitioner
Dental practitioner
Legal advice services
Church support agencies
Support groups
Marital/family therapists
Further counselling as required

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BEHAVIORAL HEALTH PLAN

HIV antibody testing is meaningless without maintaining or adopting health enhancing and/or risk reducing behaviors. Help the client reduce risk or eliminate behaviors which could lead to contracting AIDS or ARC or transmitting the virus to others. **The behavioral change is important for everyone regardless of the HIV test result.**

The goal for the HIV antibody positive individual is to remain asymptomatic and to not infect others. The goal for the HIV antibody negative individual is to remain negative.

Safer Sex Practices -

Review current sexual practices. Have client identify activities that can be modified and made safer.

Instruct client how to incorporate safer sex practices into his/her usual sexual activities. Encourage safer sex as an enhancement of the sexual experience.

Setting Behavioral Goals -

Select strategies to reach the goals.

Goals must be **meaningful and attainable.**

Goals must be **stated in specific terms, not too general.Break goals into small steps.** Don't allow the client to set him/herself up for failure.ex: I want to learn how to have safe and enjoyable sex.ex: My lover and I will try 3 different brands of condoms during the next week.

Positive Effects of Health Planning -

Reduce feelings of hopelessness and helplessness.

Gives the client a sense of control. Gets the client involved in his/her health and encourages taking responsibility.

Implementing Behavior Change Can Be Difficult -

The client will need support and encouragement. Assist the client to develop a support system.

HIV COUNSELING POINTS

- The counseling sessions begins as soon as you greet the client.

- While individuals vary greatly in how they respond to being informed of either positive or negative test results, there are nevertheless generic steps counselors take in guiding their clients through this experience.

- When delivering the news of a negative test result, the counselor helps the client realize that he/she must adopt responsible practices if he/she is to remain negative--that a negative test does not mean that he/she is immune to HIV infection in spite of past high risk behavior.

- There is a format for informing a client of HIV test results.

    1) Adequate preparation for the post-test counseling session. This is one of the most difficult and delicate interchanges between a counselor and a client. Make certain the right results are matched with the right client.

    2) Delivery of test results, in a way that will minimize client anxiety.

    3) Assess the client's reaction and stabilize possible client crisis, exercising counseling techniques that give the client both space and support.

    4) Assist the client to develop a short-term plan for handling the results.

    5) Work with the client on HIV-related issues in developing a behavioral health plan.

- Counselors use the presentation of negative results as an opportunity to reinforce risk reduction behavior.

- Counselors are culturally sensitive in finding methods to encourage behavior change.

- Counselors take note of client affect and respond to client feelings.

- Counselors are comfortable letting the client have space...periods of silence... during which the client is emotionally or mentally assimilating the test result and its implications.

THE COUNSELING SESSION

The mood of the session is important for establishing rapport and for prompting the processing of educational information. The session begins as soon as the client's code number is called. Begin to establish rapport with the client while walking to the counseling room. Clients read messages in your body language. Be aware of your tone of voice, eye contact, etc.

Counseling is helpful for the client in understanding critical information about AIDS risk reduction.

Risk reduction behaviors can be maintained or improved as a result of the testing process.

The testing experience has a powerful impact on the emotional state of the person. The expected outcome for those with negative results can be great relief and mood improvement.

Heightened anxiety and depression can be expected for those with positive results.

Irrespective of mood changes both can be motivated to continue safe sex practices and risk reduction behaviors.

Negatives wish to remain negative.

Positives want to stay as healthy as possible and to not infect others.

Clients report that it was most helpful to talk with someone about their feelings and concerns. This clarifies or increases their understanding of risk factors or behavior. Important variables are the client's level of information or misinformation. The client's motivation for taking the test. Most clients are anxious to know the results immediately, while others may need more time to be ready to hear the result. Some may decide not to receive the results. Many appreciate not receiving results at beginning of session. Each person and each session is unique. There is no set format for these sessions.

Questions: To open the result session, to elicit information to direct the interview.

1. What was it like for you during this time waiting for your results?
2. What has your anxiety level been waiting for the results?
3. Do you have any unanswered questions from the pre-test counseling (education) session?
4. How did you decide to take the test?
5. What result have you been expecting?
6. What do you see as your risks for being infected(or for that result)?
7. What leads you to believe that you may have been exposed to the AIDS virus?

* Religious beliefs are a source of support for many individuals and are to be considered and encouraged.

(You will be providing emotional support for most of the session. This is not a psychotherapy session. Don't encourage highly emotional responses). Inquire about suicidal and homicidal intention.

Accurately assess the seriousness of the intent. This can be done by asking about previous attempts. Develop a **"NO SUICIDE"** contract with the client. Consider psychiatric referral. Outpatient, inpatient.

For the rare instance of acute psychiatric reactions a contingency plan needs to be in place. (Mental health liaison.) Legal responsibilities - notifying potential objects of violence. Activate mobile emergency response team or 911 in the event of an acute emergency.

Test Information Management Plan

Decide who needs to know test results, how to tell them, when to tell and what to tell. Develop strategies for:

- telling physicians, dentist, insurance companies and employers.
- sharing information with past or present sexual partners, friends or family members.
- telling significant others - powerful impact that can be threatening to relationships - needs to be dealt with sensitively.
    * discuss strategies for telling a particular person. Try role-playing situation.
    * offer couple counseling for sharing results with significant other(s).

Referrals

Assess the client's need for resources and information. Make appropriate referrals for medical and social services. Evaluate the client's support system. Look for supports within the client's established social system that will assist him/her to maintain the health plan, and provide emotional support. Encourage involvement in support groups or additional individual counseling.Give the client written information to take home. Do not expect the client to remember all the factual information given during the counseling session.

Give the client a contact phone number (797-3533 or 332-AIDS) for any concerns or questions that arise in the future.

Summary

Summarize and review the most salient points of the counseling session. Provide an opportunity for the client to ask any remaining questions.

- Counselors are skilled at assessing client knowledge level of the antibody test, probing the client for comprehension. Explain the accuracy of the test if the client questions its validity.

- Following an appropriate interval during which the client has an opportunity to absorb the test result, the counselor tries to assess if the client understands the implications of the test result and assists the client to think through these implications.

- Counselors explain confidentiality rights and assist clients to consider the consequences of disclosure.

- Counselors help the client to assess his/her personal support system.

- Counselors reinforce that clients must pursue responsible practices.

- Denial is a frequent response to a positive test result.

- Even with pre-test counseling, some clients retain a misconception of how the test works and what its results really mean.

- Sometimes the trauma of receiving a positive result is too much for a client to rationally handle.

- A desire to retake the test is usually an avoidance of facing the results. The counselor explains the accuracy of the test and the unlikely chance of a False positive, particularly given past high-risk behavior.

- A positive test result tends to isolate an individual emotionally, socially and medically. The counselor works with the client to lessen this impact.

- No matter how stubbornly resistant a client may remain to accepting his/her test result, the counselor uses the session as an opportunity to reinforce the need for a client to follow responsible practices.

- A client cannot be restrained and/or forced into a counseling session. In the situation where the client only wants to receive his/her results, give the result, ask if there are any questions, let him know you are available for future questions or concerns. It is unproductive to exacerbate the anxiety by forcing the client to sit through a lecture. For counseling to occur there must be a two-way exchange of communication.

- Many clients experience shock upon learning that they have tested positive, the counselor recognizes the signs of shock and knows how to deal with it.

- Counselors, while knowing that they have specific information to impart to the client, allow the client to "drive" the session. The needed HIV-specific information is imported without blocking the client's emotional reaction.

- Counselors assist clients in dealing with the consequences of a positive test by helping the client compartmentalize his/her concerns and deal with each concern separately.

- Counselors can help clients work through how to inform intimates by role playing these situations.

- Counselors assure themselves by the end of the session that the client has a full and specific understanding of what it means to pursue "responsible practices".

- If a client has a strong emotional reaction, the counselor deals with the emotions and immediate decisions in the initial session. Setting follow-up appointments and having prepared information on referrals to medical care and support services can help get the client to delay confronting all issues in the first session.

POSITIVE LANGUAGE

A primary goal of educational program is to reduce fear and discrimination. The language we use in discussing HIV infection is crucial to accomplishing this. The use of inflammatory or isolating language promotes medical misinformation, fear and discrimination. Think before you speak! What images do the phrases "AIDS test", "AIDS Virus", "AIDS Carrier", "AIDS Blood" or "AIDS Victim" conjure up in your mind? Below is a list of the appropriate terms and phrases to use when discussing HIV infection!

RESPONSIBLE SEX - in place of Safer Sex. To quote Jim Klemcheck, "Safer sex is between your ears, responsible sex is between your legs"! Our goal is motivating behavior change. Being responsible means taking control of our behaviors. Safer is a state of mind!

HIV INFECTION, HIV SPECTRUM DISEASE - in place of AIDS or ARC.

HUMAN SEXUAL BEHAVIORS - not gay sex, strait sex, etc. most sexual practices can be engaged in by anyone regardless of sexual orientation.

HIV ANTIBODY TEST - not AIDS test (there is not "test" for AIDS.

PERSON LIVING WITH AIDS (PLA) - more current than PWA, more appropriate than AIDS victim.

HUMAN IMMUNODEFICIENCY VIRUS (HIV) - Not AIDS virus.

SEXUALLY ACTIVE - not promiscuous.

HIGH RISK BEHAVIOR - not high risk groups or vices. Anyone from any population group can engage in the behaviors that put one at risk for HIV infection.

GUIDE FOR PROVIDING PRETESTING INFORMATION ABOUT HIV ANTIBODY TESTING

I. Introduction

The session is enhanced if the client can review information beforehand, like a handout to refer to during the session and then take home.

A. Introduce yourself and your professional role.

B. Define the purpose of the session.

C. Explain confidentiality; prepare to address client concerns which may include:* Job* Housing* Insurance* How your agency will use information* Current and future health status.

II. Assessment

A. **Assess why the client wants the test**, if that is the reason for the session. Low risk clients may have misconceptions about the test and may need to be triaged to other services. If the exposure occurred less than 6 weeks previously, sufficient time for seroconversion has not elapsed. Questions that can help this assessment include:

* "Why do you want to take the test?"
* "When were you exposed to someone who might be affected?"
* "When were you last tested? Why? Where? What was the result? (If less than 3 months, tell the client that the test results may not be valid.)

B. **Describe the Testing Procedure**-What will happen if the client decides to take the test (i.e., blood taken from the arm; results available on a certain day; efforts to preserve confidentiality [or anonymity]; results only given in person).

C. **Provide the client with information about AIDS and the HIV antibody rest.**

* TEST PURPOSE-The test is for antibodies to HIV--it does not diagnose AIDS or tell whether the individual will get AIDS.
* AIDS PROGNOSIS-60% to 70% of people who test positive do not develop AIDS within seven years of infection.
* MEANING OF TEST RESULTS-There are three possible outcomes: negative, positive, and uncertain (equivocal).

1. NEGATIVE-A negative test usually means that an individual is free of the virus. However, anyone who has had "unsafe sex" or shared needles with infected persons in the last 3 months may be infected and later develop a positive test. Anyone at increased risk of acquiring HIV who is currently negative should take control and reduce those risks. This includes having any sex partners tested for the virus.
2. POSITIVE-A positive test indicates infection with HIV and the ability to transmit it to others by sexual contact, sharing of IV needles, or by mother to unborn child or infant.
3. EQUIVOCAL-Occasionally, the test result is uncertain. The laboratory cannot definitely tell whether the test is negative or positive. It is recommended that the client submit another blood specimen for testing when this occurs.

* TEST VALUE-Some people don't take the test, yet adjust their behavior to avoid catching or passing the virus. Other people find the test helpful in making meaningful plans. If you're negative, you'll know what you must do to help avoid infection. If you're positive, you'll know what you must do to protect others and to help you avoid illness or developing AIDS.

D. **Find out if client intends to take the test.** "What other questions do you have about the test?" "What is your decision about taking the test?" (If yes, proceed. If no, skip to III and omit IV.)

E. **Assess the impact of test results on the client's lifestyle**. Any HIV antibody test result can have a significant psychological impact on both the individual tested and those who are close to him or her. The following or similar questions can help with this assessment:

* "What are your expectations about the test results?"
* "What would a positive test mean for you?"
* "What changes will you make in your life if you're positive?"
* "What would a negative test mean for you?"
* "What changes will you make in your life if you're negative?"

F. **Assess how the client plans to handle the waiting time until the test results are received**, and give reasons for not getting unduly upset. The following questions can help with this assessment:

* "How do you plan to cope while you are waiting for test results?"*
* "What plans have you made to tell anyone that you had the test done?"

* Emphasize that a person who takes the test should plan to return; even if they have second thoughts about learning their results and whether

they're infected, they should still return to discuss their situation and available support services for making changes to reduce risk.

III. Prevention Recommendations

These messages may be given at any opportune time and be more effective when delivered with the support of written material. Clients should be made to understand that HIV infection is passed by infected individuals through sex, sharing needles, and exposure to blood; and from infected mothers to their unborn or nursing children. It is better to assess a client's knowledge, plans, and behavior by leading with open-ended questions (using words like what, how when, etc.) and responding to answers than by simply lecturing.

* BEHAVE AS IF POSITIVE until a counselor says negative test results are valid.
* ABSTINENCE FROM SEX AND DRUGS is the surest way to avoid catching or passing the virus.
* A MUTUALLY MONOGAMOUS RELATIONSHIP is the choice of many these days and will work if both partners enter the relationship virus-free.
* LIMIT THE NUMBER OF SEX PARTNERS if abstinence or monogamy is not possible. Selecting your partners is also important, because risky behavior by even one partner can put you at risk too.
* USE CONDOMS from start to finish with partners whose antibody status is not known to be negative. When having sex, avoid passing or receiving body fluids, particularly blood, semen and vaginal secretions. You should take the time to learn how to make condoms more effective for you. (A detailed handout is helpful here.)
* ENROLL OR CONTINUE IN A DRUG TREATMENT PROGRAM(For IV drug abusers).
* DO NOT SHARE NEEDLES, including syringes and "works,"if abstinence from drugs is not possible.
* DO NOT USE "POPPERS"-Amyl and butyl nitrites.
* OBTAIN FAMILY PLANNING ASSISTANCE-(For non contracepting women of child-bearing age with risk factors for HIV -- move this to the top of the list of measures to prevent HIV infection.)

IV.Partner Notification

Inform the client that if the test is positive we will strongly encourage that sex and needle-sharing partners be informed and given the opportunity to be counseled and tested. We will help the individual to do this by offering various techniques and suggestions to sensitively discuss the subject and may assist by notifying partners if they prefer.

V. Conclusion

A. Address any questions the client may have.

B. Provide a handout reinforcing the prevention recommendations. Give information and condoms when appropriate.

C. Make sure the client knows when to return for test results and that they will be discussed at that time.

D. Advise the client that there may be a different post-test counselor.

INTERACTIONAL METHOD OF PRE-HIV-ANTIBODY-TEST COUNSELING

Mr./Ms. , You have requested (it has been recommended that you undergo) HIV-antibody testing, commonly known as the "AIDS blood test." What is your understanding about that test?

> [**Allow** time for the patient to answer; if he/she hesitates or says "I do not know," encourage the patient to give his/her best understanding.]
>
> [**Clarify** the information, if needed, after each answer.]

The HIV-antibody test measures the presence of antibody, or the protein made by your body to fight infection (for example, you normally produce antibody after a vaccination). HIV is another name for the AIDS virus. If you show antibody to the AIDS virus, then we judge that you are infected with the AIDS virus. Even then, it would not mean that you have AIDS or that you will get AIDS. It will mean that you are at risk for getting AIDS. If that is the case we will talk about things you can do to lower that risk. If you do not show antibody to the AIDS virus, it will mean you are not infected so long as you have not been involved in risky behaviors over about the last six months.

What are the limitations of the test?

The test will accurately tell if you are infected with HIV, but it **does not** predict whether you will become sick with AIDS or not. If a first test of your blood indicates HIV infection, a second and different test will be done on that same blood sample to be as certain as possible about your results. Only if both tests are positive, in other words both tests show a presence of antibodies to the virus, will you be told that you are infected. If the results of the two tests done on your blood do not agree (the first test is positive and the second is negative), we will advise you to have the test repeated in three to six months. Very occasionally, the results of the two blood tests will both be incorrect and a person is identified as being infected when he/she is not. If a person doubts the result, he/she should be retested.

It is possible for someone to be infected during the six months or so prior to the test and for the blood test to be negative, or in other words, for the test to falsely show no infection. Thus, if someone has participated in at-risk behaviors with another person recently, it is necessary that he/she have another test in three to six months.

What can you learn from the test results?

The test will reliably determine whether you are infected and can infect another person with the AIDS virus.

[Review with the patient responses to the first two questions which he/she should repeat in responding to this question.]

Mr./Ms. , how is the virus transmitted or spread from one infected person to another?

[Again, allow the client time to answer; encourage the answer by saying "Tell me more" or "Go on." If the client states that he/she does not know, ask the patient to "Give your best understanding based upon what you have heard or read."

The AIDS virus is spread from one person to another primarily by rectal and/or vaginal sexual intercourse, or by oral sex, by sharing intravenous needles and syringes used by others, or through pregnancy where a woman transmits the virus to her baby still in the womb.

A person can appear healthy and still be a virus carrier, infecting other people by the method noted above, without ever becoming sick himself or herself.

What can you do to reduce the danger of HIV infection to yourself and to other people?

A person decreases the risk of becoming infected and of infecting others with the virus by practicing sexual abstinence ("No sex") or by having only one sex partner who is not infected, by using latex rubber condoms with nonoxynol-9 spermicide (obtained without a prescription as a gel or foam) during oral sex or sexual intercourse, and by never using a needle, syringe, or other drug paraphernalia ("works") after it has been used by another person.

If a person chooses to use syringes and needles used by another person, he/she should wash the "works" (including cotton, caps and cooker) with household laundry bleach two times and then rise thoroughly with clean water. Alcohol and water alone are not effective in killing the virus.

[Review and repeat responses, varying wording as necessary, to achieve maximum understanding.

PATIENT COUNSELING ABOUT AIDS ANTIBODY TEST RESULTS

The AIDS antibody is a protein naturally produced in the body in response to the HIV - the virus that causes AIDS. The test is not completely accurate. The test will not tell you if you have AIDS or ARC. It will not tell you if you will develop AIDS or ARC in the future. It will not tell you if you are immune.

A POSITIVE TEST RESULT DOES MEAN:

- antibodies to the HIV are present in your blood
- you have been infected with the HIV and your body has produced antibodies
- you probably have active virus in your body and should assume that you are capable of passing the virus to others

A POSITIVE TEST RESULT DOES NOT MEAN:

- you necessarily have AIDS or ARC
- you necessarily will develop AIDS or ARC in the future
- you are immune to AIDS

A NEGATIVE TEST RESULT DOES MEAN:

- antibodies to the HIV are not present in your blood at this time
- three possible reasons for the negative result are:
  (1) you have not been infected with the HIV; OR
  (2) you have had contact with the HIV but have not become infected and therefore have not produced antibodies; OR
  (3) you have been infected with the HIV but have not produced antibodies (which can take 2 weeks to 6 months, or longer)

A NEGATIVE TEST RESULT DOES NOT MEAN:

- you have nothing to worry about. AIDS is still at epidemic proportions
- you are immune to the HIV
- you have not yet been infected with the HIV; you may have been infected and not yet produced antibodies

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SOURCE: G. Carr and G. Gee, "AIDS-Related Conditions: Screening for Populations at Risk," in AIDS: Concepts for Nursing Practice, edited by G. Gee and T. Moran. Williams & Wilkins Publishers, Baltimore, MD. 1988.

In Pre-Test Counseling

(A) You have found out:

Why client wanted to be tested

How s/he thinks infection might have occurred

When last exposed

Who client is:

psychological profile
past stressors
coping skills
communication skills
network (support system-friends, lover, family, religious)
level of functioning (living arrangement, employment status)

What reaction might be to positive test, negative test

(B) You have educated client to tests, value of results and what results mean.

(C) Given client recommended guidelines based on results:

Negative = prevention of future infection

no immunity
safer sex practice
risk behaviors and proper referrals

Positive = implication

treatment options
prevention of infecting others and reinfect self (safe sex, not doing proper cleaning of works)
notification of partner
activities that will further compromise immune system:

- rest
- adequate sleep and nutrition
- good hygiene
  unsafe activities

Post-Test Counseling

(A)Positive:

1. Unless client indicates otherwise, give results clearly and quickly

2. Frequently evaluate responses during session

    Physiological: sweating, paleness, restlessness, dry mouth

    Emotionally: inability to concentrate, fear, anger

3. Encouraging questions - What questions are asked helps you to evaluate ability to integrate given information

Have client tell you what (+) test results means to s/him both physically and emotionally

4. Review social supports discussed in pre-test session. Who, if anyone, will/should client disclose test results to

5. Importance of peer support - can't emphasize enough.

Discussion of power of peer support groups(AA, NA, Reach for Recovery, etc.)

6. Develop plan (short term) keep client focused on the immediate future. Tendency is to look to future and possible death. This is real and important to discuss, but help s/him focus on present and what actions would empower s/him.

Review Recommendations:

1. Safer sex practices and relapses

2. Risky activities (be realistic)

3. Reproductive constraints (big loss)

4. Health planning

    aggressive approach being adopted
    treatment options
    referrals

5. Address use of denial

Healthy	Unhealthy
I can't deal with this 100% of the time.	I don't want to deal with this. I'll put it out of my mind.
Going to M.D.	I feel fine, therefore I am fine and I don't need to go to the M.D.
Safer sex practices	The hell with it.

Summary:

Be concrete:

"What are you going to do after you leave here?"

"How do you feel?"

"Who are you going to discuss your test results with"AND if no one, ask why and encourage them to call you or use hot lines or mental health referral

Reinforce information with handouts

Encourage them to call when questions arise

Referral to M.D. (this is a strong indication of client denial vs. acceptance if s/he does not go to M.D. after a period of time. Give cancer analogy for early intervention.

(B) Negative

If no relief evident, try to find out why

Strong survival guilt in partners. Give them permission to feel any/all their feelings

"Thank God I'm negative."

"That's terrible, I should feel bad that my partner is positive."

"I'm crazy not to be happy but I want to be like s/him."

Reinforce ways to stay negative:

- safer sex
- number of partners
- not sharing works
- cleaning works
- substance abuse (be realistic)

ADDITIONAL INFORMATION FOR PROVIDING POST-TEST EDUCATION AND DISCLOSURE ABOUT HIV ANTIBODY TESTING

I. Goals and Objectives

The return appointment for receiving test results is an opportunity to reinforce the messages communicated in the pre-test education. Therefore, it is important to give out consistent information at both appointments.

The process of disclosing test results is critical for several reasons and should help the client to achieve the following goals:

1) cope with the immediate psychological reactions to learning the result;

2) cope with the test result and manage the test information (whether the result is positive or negative); and,

3) develop a health plan.

See below for an elaboration of these points.

II. Procedures in Disclosure of Results

A. Establishing Rapport

Test results must be given out on an individual basis rather than in a group setting because of the confidential and sensitive nature of the information. In order to help the client feel comfortable in the disclosure session, the counselor needs to establish rapport very quickly. Basic attending behaviors such as establishing eye contact, empathic listening and responding, and introducing yourself, ("being with the person") will facilitate this process. It is important to acknowledge that the client's response to the counselor's behavior may vary with the client's race and cultural background.

In many instances, clients may prefer a counselor of the same sex or sexual orientation. These provisions can potentially provide a base of trust and mutual understanding which might facilitate open, effective discussion.

At the very least, the counselor should be well-informed regarding cross-cultural counseling issues as well as issues specific to gay and bisexual men, IV drug users, women, people of color, and individuals who earn their livelihood in the sex industry.

A counselor needs to be constantly aware of the set of physiological, psychological, and social factors which are unique to the individual client. The more the counselor has an awareness of and sensitivity to these factors, the greater the possibility for effective communication.

Notice the bodily reactions. The client may be visibly nervous, with trembling hands, sweaty palms, increased pulse rate or muscular tension (especially in the face). Even more important are psychosocial variables, especially the client's expectations of a positive or negative result and his/her perceived risk (whether it is realistic or unrealistic), degree of anxiety, ability to cope with stressful events and the client's reason(s) for taking the test. It is important to know about the quality of a client's social support system. For example, do other persons know about the client's situation? If so, are they people the client can trust with confidential information and can the client receive unconditional support from these people.

Clients should be given the opportunity to ask questions before they receive their result. The following questions can be helpful for starting the communication:

A) "Do you have any questions from the pre-test education that you want to ask now?"

B) "How did you decide to take the test?"

C) "What leads you to believe you may have been exposed to the AIDS virus?"

The answers can be useful for directing the interview, interpreting the results, and linking the client to appropriate resources. For example, the focus of the session will be different for a sexually active gay man than for a woman who used intravenous drugs.

However, it is important for the counselor to recognize that most clients will be anxious and want to know the test result immediately. They may experience extensive questioning prior to giving the result as unnecessarily prolonging their anxiety. Some may need more time before they may be ready to hear their result, while a handful of clients may even decide not to receive the result. Being sensitive to the client's needs and allowing the client to take the lead in deciding when the test result is delivered may afford the individual some needed sense of control. It is extremely important to note that any of the information listed in this section can be elicited following the delivery of the test results.

B. Revelation of the Test Result

The actual revelation of the test result has proven to be most effective when presented in a straightforward manner. This means telling the result with direct eye contact and without undue expression of concern:

A) "Your test result came back positive" or

B) "Your ELISA test shows that you were positive on three consecutive tests. When you're ready, we can talk about the meaning of that."

Once the test result is delivered, the counselor should resist the temptation to fill the silence and wait for the client to respond. By observing verbal and non-verbal cues (especially face and eyes), the counselor can determine when the client is ready to talk about the result.

The counselor should demonstrate empathy to the client's reaction by comments such as:

A) "It sounds like you're feeling relieved about your negative result" or

B) "Even though you expected positive result,it is still frightening to actually hear it now."

Note that these comments reflect the client's response rather than interpreting or judging it. If the client does not respond verbally for an extended period, the counselor may ask:

A) "What does this mean to you?" or

B) "What are you feeling about that?"

Clients will respond in various ways to the revelation of the test result. While some may be shocked and unable to speak, others will express different, often strong emotions like anger (either at themselves, a partner, or even the counselor), sadness, fear, joy or relief. Since this is not a psychotherapy session, the counselor should not actively encourage highly emotional responses. However, the affective response to the test result is a primary indicator for directing the rest of the session. The counselor should listen carefully and reflect the client's statements to convey understanding and help the client move on to integrate the given information.

C. Integrating the Test Result

The next step after the disclosure of the result involves helping the client accomplish four important goals:

- to understand the result cognitively; this includes medical knowledge as well as the impact on the person's life.
- to assimilate the emotional impact of the test result.
- To develop a behavioral health plan that will reduce or eliminate the possibility of becoming infected or infecting others; and reduce his/her chances of developing AIDS or ARC.
- to develop a strategy for dealing with the interpersonal ramifications of the test result.

1. Cognitive Integration or "What Does My Result Really Mean?"

Though every client should know what a positive or a negative test result means after the pre-test education, it is very different to deal with the discovery of one's own test result. Furthermore, it is also difficult to assimilate the given medical information at a time of emotional turmoil. For example, a person may know intellectually that a positive test result does not imply a diagnosis of AIDS, but he/she may still interpret it that way emotionally. Therefore, the counselor should inquire about the client's interpretation of his/her result after disclosure. This can be accomplished in several ways. The counselor can have the client demonstrate his or her understanding by posing key questions, such as the following:

A) "Now that you know your test results,how do you interpret that information?" OR

B) "How do you understand the meaning of being positive (or negative)?"

Once the counselor ascertains the client's level of understanding, the counselor can modify or correct any misunderstandings and reiterate the main points of test interpretation. Additionally, the counselor can refer the client to written materials.

Another dimension of cognitive integration is related to the personal meaning of the test result. Since a result is not received in a vacuum but in the context of one's whole life, it may raise questions related to important themes such as relationships, sexuality, childbearing, parenthood, religion, philosophy, alienation or death. Even though time constraints usually preclude lengthy discussions on these topics, counselors need to be aware of their relevance.

Counselors can reaffirm the value of these questions and encourage further exploration in another setting.

2. Affective Integration or "How Could This Be Happening to Me?"

To help the client assimilate the emotional impact of a test result, he/she should be allowed to express feelings freely. This kind of release has a cathartic value and may reveal fundamental beliefs, conflicts, and coping styles.

Experience has shown that some clients will either distort, ruminate excessively, or exaggerate the implications of a positive test result. However, given that a positive test result is a strong indicator of those who will most likely develop AIDS or ARC, it is important to validate fears of future diagnosis. Often clients will have a difficult adjustment period that lasts about a month. Counselors may wish to let a person know about this and thereby normalize the emotional reactions. Informing clients about these common emotional responses or difficulties in coping can decrease the level of stress experienced by the client.

Receiving a test result (even a negative one for some) has such an emotional impact that the counselor may need to provide emotional support for most of the session. A few clients may even express suicidal or homicidal intent. The seriousness of these statements needs to be assessed and acted upon. This may involve asking the client about previous attempts, developing a "no-suicide contract," or referring to outpatient or inpatient psychiatric services. In extremely rare instances, legal authorities or potential objects of violence may need to be informed. Contingency plans for these situations should be developed well ahead of time and should most appropriately be handled by mental health professionals.

The goal of this intervention is to enable the client to leave the session at least relatively intact. If there is no time left for discussion of AIDS risk reduction and other pertinent issues, the counselor should recommend a return visit, if possible. If not, written material should be given to the client and appropriate referrals made.

3. Behavioral Integration or "What Should I Do Now?" Introducing the need for a behavioral health plan is one of the main goals of the disclosure session. Indeed, taking the test is meaningless if the client does not maintain or adopt health-enhancing and AIDS risk reduction behaviors. Besides adhering to "safer sex" practices, clients must also take other potential "co-factors" into consideration when developing a plan. These potential co-factors include

pregnancy, the use of alcohol and drugs, stress, acquiring other viral infections, or poor nutrition. Any of these may theoretically play a role in the development of AIDS by directly reducing immune function, or indirectly in the case of alcohol and drugs, by clouding judgment and thereby setting the stage for engaging in high risk activities.

Women and men considering parenthood will need to address family planning issues, including both birth control and whether or not to have children. As this may be a particularly difficult subject to resolve during a single session, referral to appropriate resource agencies will be important.

The intention of developing a health plan is to help the client reduce or eliminate behaviors which could lead to contracting AIDS or ARC or transmitting the virus to others. Following such a plan is just as important for persons who are antibody positive, as it is for those who are antibody negative. If a person is antibody positive, the goal is to stay asymptomatic, not add more virus to his/her system, and not to infect others. If antibody negative, the aim is to remain so and to protect oneself from getting infected by the AIDS virus.

A critical part of the health plan involves reviewing the safer sex practices and incorporating them into a client's lifestyle. Usually, this is necessary even if the client claims to "know" them. For a client who has used or currently uses IV drugs, it is important that he/she understands the procedure for cleaning needles.

Formulating a health plan involves setting behavioral goals and selecting strategies to accomplish these goals. These goals must be both meaningful and attainable. For example:

> "I want to learn how to have safe and enjoyable sex;"
>
> "I want to be able to talk about safe sex with my partners before we start having sex;" or,
>
> "I want to stop sharing needles."

Also, goals should not be formulated too generally, e.g., "I want to be safe," but should be stated in specific terms, e.g., "I want to learn how to use a condom." The chances of attaining these goals will be increased if they are broken down into small steps.

Useful questions to involve the client in this process are, "What steps can you take to keep yourself healthy?" or "Which kinds of things are most likely to hinder you in following your health plan?"

One positive side effect in health planning is that it can reduce feelings of hopelessness and helplessness and give the client a sense of control. However, as the implementation of these behavioral changes can be difficult, a referral to a mental health professional or substance abuse agency may be indicated. Counselors should be prepared to make referrals to AIDS knowledgeable therapists and agencies.

4. Interpersonal Integration or "Who, How, When and What to Tell?"

Receiving the results of an AIDS antibody test has important implications not only for the client, but also for other people in his or her life. Each client needs to decide who, how, when and what to tell about his/her test result, since there are potential benefits and consequences to consider. Therefore, it is essential to have a plan for managing the test information. This plan should include different strategies depending on the person who may be informed. For example, telling physicians, insurance companies or employers should be handled differently than sharing the information with past or present sexual partners, friends or family members. Telling significant others can be powerful and threatening to the relationship and needs to be dealt with sensitively. At times, discussing the details of telling a particular person or even role-playing the potentially problematic situation may be useful. (See Appendix C for more detailed information on managing test information.)

D. Summary and Referral

When ending the disclosure session, the counselor should review the most important points raised during the interview. These may include the meaning of the test result, particular concerns, e.g., consideration of parenthood, telling others, etc., risk reduction behaviors, and appropriate referral resources. This summary will help the client remember the most important aspects of the session and provide an opportunity to ask remaining questions.

At the completion of the interview, it is essential to provide appropriate resources regarding further information, medical and social services, maintenance of the health plan, and emotional support. The counselor should try to make the best possible match between the client's needs and the available resources. Written information describing various resources can also be dispensed.

III. Follow-Up

Follow-up sessions can be useful for different reasons. The disclosure session is usually emotion-laden and too brief for the client to remember every important detail. Experience has shown that some individuals (especially those who received positive test results) barely remember the content of the session because of the strong emotional reactions engendered during the interview.

Receiving a test result is a first step in a long process. Since seropositives are thought to be infectious for life, further help may be needed to establish and maintain necessary changes, especially for those who experience emotional difficulty after receiving their result. Frequently, clients have reported prolonged depression and feelings of isolation and stigmatization, impotence, and panic or anxiety disorders. While occurring in some individuals, most clients (even those with positive test results) make a satisfactory adjustment to their situation. Providing a support group has been shown to be extremely helpful for some test recipients. Also, personnel in already existing community services should be trained to provide follow-up services.

It is unknown which seropositive test recipients will go on to develop AIDS OR ARC, although current statistics from studies indicate that the majority of individuals infected with the AIDS virus will most likely develop AIDS or ARC over time. Medical follow-up should be established for continuity of care as well as evaluation of treatable diseases or infections with AIDS knowledgeable and sensitive physicians and clinics. Such follow-up is particularly important for pregnant women or seropositive women and their children. If an individual does develop AIDS or ARC, appropriate medical and social services can then be provided.

INTERACTIONAL KNOWLEDGE AND RISK ASSESSMENT: HIV INFECTION

The results of your HIV-antibody test are (negative, positive). What does this information mean to you?

Positive = person probably is infected with the virus;Negative = person probably is not infected.

Clarify information regarding positive and negative test.

What does the HIV-antibody test measure?

The test measures the presence of antibody to HIV, the virus that is thought to cause AIDS in some people. **The test is not an AIDS test.** The test measures whether or not the body has developed a substance called antibodies to fight infection.

Clarify 'antibody.'

What are the limitations of the HIV-antibody test?

There is a period of 3 to 12 months following infection with HIV before antibodies are present in sufficient quantity to be detected by the test. Individuals who have recently engaged in high-risk behaviors for being infected with HIV may be falsely reported as antibody negative.

Clarify 'HIV', 'incubation period', 'false negative'.

(If HIV antibody NEGATIVE) **Does your being HIV antibody negative mean that you can never catch HIV and get sick with AIDS?**

(No)

Clarify that subject needs to avoid high-risk behaviors.

(If antibody POSITIVE) **Does your being antibody positive mean that you will become sick with AIDS?**

Not necessarily; changing behaviors to more healthy ones may decrease the likelihood of conversion, i.e., alcohol/drug use, diet, exercise, hygiene, etc.

Clarify and **instruct** that subject can take action to reduce the likelihood of conversion to AIDS.

What percent of persons who are HIV antibody positive go on to develop AIDS in 5 years?

> **Clarify** percentage issue. One may be an asymptomatic carrier of HIV and never become ill with AIDS, but still infect others who might become ill. Once infected with HIV, one is infectious to others indefinitely.

What are the symptoms of AIDS?

An illness characterized by fever, night sweats, weight loss, recurrent infections, persistent flu-like symptoms, with physical deterioration and ultimately death.

> **Clarify** and **instruct** regarding symptoms of AIDS.

How is HIV infection spread from one person to another?

> Sexual relations [usually vaginal or rectal intercourse and oral sex], sharing IV needle-syringe paraphernalia, mother to fetus, blood transfusions.
>
> **Clarify** and **instruct** regarding high-risk behaviors, explaining that virus is transmitted in blood, semen, or vaginal secretions. Ask subject to repeat the list of high-risk behaviors. For seropositive subjects, point out the subject's responsibility for acting to avoid infecting others.

How can people prevent spreading or contracting HIV or the virus that causes AIDS?

> By practicing sexual abstinence, sex with one partner, using latex condoms with spermicide, not sharing drug paraphernalia such as syringes, needles, caps or cotton, controlling drug/alcohol intake, use bleach for cleaning drug paraphernalia if he/she believes "works" have already been used.
>
> **Clarify** with subject after he/she volunteers the above. **Instruct regarding measures that subject did not mention. Point out need for latex condoms with spermicide.**

Have you made any changes in your behavior to avoid getting HIV and possibly getting sick with AIDS? What have you done?

> **Clarify** the need for behavior change.
> **Clarify** the need for future (3 months later) HIV antibody testing if HIV antibody negative and high-risk behaviors in the last year. If ELISA positive and Western blot negative (equivocal result), recommend retesting in 3 months by physician or public health agency.

Give card with address and telephone number of public agency.(If HIV antibody POSITIVE):

Recommend that subject not donate blood, semen, or body organs. Also **recommend** that subject practice safer sex (described previously) in order to avoid infecting others; that subject not share personal items such as toothbrushes or razors; that subjects defer pregnancy or seek counseling if pregnant because of the risk of fetal infection; that subject inform others who may have been infected by sexual practices or by shared paraphernalia such that they may seek HIV testing; and recommend that subject inform his/her dentist and physician regarding the positive HIV antibody status.

Clarify that HIV is not spread through casual contact.

What did you think of this information session? What have been your feelings about discussing such an important and personal matter? Any questions or comments about the session?

Allow subject to ventilate and react to the session.

Are there issues about which you would like additional information?

"Are there people at home who you think should be tested for HIV antibody as well? Will you share information materials and the information that you have learned here? You may give others this card with the telephone number and address of a public health agency where further information and testing are available."

Would you want to meet again to discuss any of the things that we have discussed today?

Make arrangements for follow-up or another session to clarify or react to information.

Notes:

Date______________ Reviewer______________________________________

-STAFF GUIDE-
FOR COUNSELING PEOPLE WITH SERONEGATIVE HIV ANTIBODY TEST RESULTS

I. THE TEST RESULTS

Give results. Immediately provide feedback to the client by using the following information:

***TEST PURPOSE:** This is a test for antibodies to HIV.

***RISKS REMAIN:** Despite your negative result, infection is still possible if you had unsafe sex or shared needles in the past 3 months. Also, this does not mean immunity to the virus.Someone may have HIV but not yet develop enough antibody for the test to measure.

***RETESTING:** Retesting is not recommended unless there has been unsafe sex or needle sharing in the past 3 months. Testing less than 6 weeks after HIV exposure may fail to detect seroconversion.

***REGULAR PARTNER:** If any of the client's regular sex or needle sharing partners are positive, point out that: 1) condoms should be used whenever you have sex; 2) condoms can fail, even with proper use; 3) receptive anal sex is very risky,even using a condom; and 4) the client should seek counseling/testing every 3-6 months if unprotected exposures continue.

II. RISK REDUCTION

Inform the client about what can be done to decrease the risk of acquiring HIV. By asking open-ended questions (using words like what, how, when, etc.), find out what the client knows and intends to do before giving educational messages. Use the following risk reduction messages, preferably by referring to a more detailed handout.

***ABSTINENCE FROM SEX AND DRUGS** is the surest way to avoid infection with HIV or passing it to others.

***A MUTUALLY MONOGAMOUS RELATIONSHIP** is the choice of many these days and will work if both partners enter the relationship free of the virus.

***LIMIT SEX** to seronegative partner(s). To be sure, both partners must be seronegative 3 months after the last risky behavior.

***USE CONDOMS** from start to finish when having sex with anyone whose antibody status is not known. When having sex with these people, do not pass or receive body fluids, particularly blood, semen, or vaginal secretions. Know the facts about correct condom usage.

***ENROLL OR STAY IN A DRUG TREATMENT PROGRAM** if using IV drugs.(If the client is not under treatment but still shares needles and/or is a woman 15-44, discuss ways prearranged to expedite enrollment.)

***DO NOT SHARE NEEDLES**, including syringes and "works," if abstinence from drugs is not possible or immediate enrollment in a treatment program cannot be arranged. You must assume that sharing of needles will at some time occur,therefore, persons should be taught how to properly clean needles and "works".

***DO NOT USE "POPPERS"**, such as amyl and butyl nitrates.

B. For any male client who has had sex with another man since 1978 or any client who has used IV drugs since 1978,advise against donating blood, plasma, tissue, or sperm-despite the negative test. Women should be cautioned against artificial insemination.

C. Again, using open-ended questions, ask about the client's plans to remain negative and for reducing the chances of acquiring the virus.

III. OVERVIEW

A. Address any **questions** the client has.

B. Provide a **handout** to reinforce the prevention recommendations.

C. Provide information about telephone **hotlines** and any support groups that might assist people in adopting lifestyles that reduce or eliminate the risk of HIV infection.

D. Provide handouts on **condom** usage and condoms when available and appropriate.

E. Discuss **retesting** if the client has had a high-risk exposure within the past 3 months.

F. Be prepared to **refer** the client for follow-up support services or mental health counseling if the person is at high-risk and is obviously going to have problems changing behavior, or is in a crisis, e.g., experiencing "survivor syndrome" depression and/or guilt.

-STAFF GUIDE-
FOR COUNSELING PEOPLE WITH SEROPOSITIVE HIV ANTIBODY TEST RESULTS

I. THE TEST RESULT

Give results. Immediately provide positive feedback to the client by using the following information. It is important throughout the session that the counselor assess if the client understands the messages before proceeding.

***NATURAL HISTORY OF INFECTION:** Your positive result does not mean you have AIDS or that you will get it. At least within the first 5 years, 60-70% of people with a positive test do not develop AIDS.

***TEST MEANING:** A positive test by itself does not diagnose AIDS;it detects antibody to HIV. It does mean you are infected and can transmit it to your sex or needle-sharing partners. A woman can pass the virus to her child during pregnancy or birth or possibly through breast milk.

***CONTROL:** What you decide to do may be a factor in determining whether or not you develop AIDS.

***IMMUNE SYSTEM:** AIDS occurs IF the virus multiplies enough to overwhelm the body's defense system. Laboratory evidence suggests that the virus multiplies faster when the body's defense system becomes active. Although this is not the only time that the virus multiplies, it seems wise to lessen the chances of activating your defense system. The virus seems to multiply when your immune system is busy fighting off some other infection, i.e., sexually transmitted diseases, etc.

***PROTECT YOUR HEALTH:** By avoiding infections (such as sexually transmitted diseases) that might cause the immune system to become active, you may be able to delay or prevent the onset of AIDS.

***CONSIDER SUPPORT:** Many areas have support groups to assist infected people understand and cope with their infections.

II. RISK REDUCTION

Present these messages in conjunction with appropriate handouts. They may be delivered at any point in the session in response to client needs. It is best to assess a client's knowledge, plans, and behavior by leading with open-ended questions (using words like what, how, when, etc.) and responding to answers than by simply lecturing.

A. Provide the following risk reduction messages to protect the client:

***ABSTINENCE FROM SEX AND DRUGS** is the surest way to avoid reinfection and passing HIV to others. Exposing yourself to infections can trigger your body's defense system and possibly more rapid multiplication of the virus.

***LIMIT THE NUMBER OF SEX PARTNERS** if abstinence is not possible. Selecting your partners is also important, because risky behavior in even one partner can put you at risk too.

***DO NOT PASS OR RECEIVE BODY FLUIDS DURING SEX** - especially blood, semen, and vaginal secretions.

***USE CONDOMS** properly from start to finish. They can protect against passing HIV and exposure to other infections. However, condoms do not protect 100 percent of the time, and there are things you should know about condoms to make them more effective. Receptive anal intercourse, even with a condom is particularly risky. (A detailed handout is helpful here.)

***ENROLL OR STAY IN DRUG TREATMENT PROGRAM** if using IV drugs. (If the client is not under treatment but is still sharing needles and/or is a woman 15-44, discuss ways to expedite enrollment.

***DO NOT SHARE NEEDLES,** including syringes and "works", if drug abstinence or prompt enrollment in treatment program is not possible. A person should be taught how to clean syringes and "works" if it unrealistic to think they would not continue to share equipment.

***DO NOT USE "POPPERS",** such as amyl and butyl nitrates.

***CONSULT A PHYSICIAN,** depending on local policy, for evaluation and follow-up. If not local policy, describe symptoms which should signal a visit to a physician. People with impaired immune systems may benefit from flu and pneumococcal vaccines.

***OBTAIN EVALUATION FOR TUBERCULOSIS.** Patients with HIV antibody who also have positive TB skin tests or radiographic evidence of TB should be referred for treatment.

B. Additional risk reduction recommendations the client should follow to prevent spread:

***DO NOT DONATE** blood, plasma, body organs, other tissue, or sperm.

***AVOID BECOMING PREGNANT:** (for all women of childbearing age)

***AVOID CAUSING PREGNANCY:** (directed to bisexual and hetero sexual men).

* **DO NOT SHARE** toothbrushes, razors, or other items that could become contaminated with blood.

* **CLEAN AND DISINFECT SURFACES** on which blood or other body fluids have spilled (a 10% bleach solution is effective).

* **INFORM PERSONAL HEALTH CARE PROVIDERS,** physicians, dentists, and other health care workers, of antibody status when seeking care.

C. **Summarize:** Reducing risk and staying healthy are things the patient can do to lower the odds of developing AIDS or infecting others.

IV. NOTIFICATION OF SEX AND NEEDLE-SHARING PARTNERS

Local program policy will dictate the extent to which health personnel can participate in this process.

A. Assess the client's plan for notifying sex and needle-sharing partners (for practical reasons, locatable partners exposed in the last 1-2 years) about the positive test results (e.g., the plan for telling them, what to say, and how to handle their reaction).

B. Based on responses, coach the client on what to say and how to say it. Important points to cover during the coaching process are:

- Informing the partner in a private setting.
- Avoid accusations.
- Anticipating that partner(s) may be upset or hostile.
- Urging partners to be counseled and tested as soon as possible.

C. If the client is unwilling to inform partner(s) and is adverse to providing information for health department staff to make the notification, the counselor can use the following motivations:

* **PARTNER CONSIDERATION:** Partners have a right to know they have been exposed to the virus and be given a chance to seek a medical evaluation. Only the patient knows who these people are and about their exposure to HIV; denying them such vital knowledge about their health may result in serious consequences.

* **PARTNERS SPREAD:** Positive partners may unknowingly spread the virus to others.

* **FEMALES:** Infected female partners need to be advised about avoiding pregnancy.

***PREGNANCY:** Infected female partners who are pregnant need an immediate referral for medical evaluation.

V. CONCLUSION

A. Address any questions the client has.

B. Reinforce client's commitment to get a TB skin test and to follow other recommendations for risk reduction,especially condom use and avoiding sexually transmitted diseases.

C. Provide handouts which reinforce the prevention recommendations and detailed information on condoms when applicable.

D. Provide other materials as appropriate (including pamphlets, condoms, telephone numbers and information about support groups, TB skin testing, family planning facilities,physicians, etc.).

E. Discuss what might happen if the client tells anybody,other than those recommended, about his or her infection.

F. Make any referrals which seem indicated to medical or follow-up support services or mental health counseling, particularly if the client has symptoms, seems unable to cope with infection or make risk reducing behavior changes without assistance, or is in acute distress.

HIV SEROPOSITIVITY DISCLOSURE

Activity: Ask person(s) to indicate their agreement/disagreement with the following statements:

1. Persons who are HIV seropositive need to tell:

   a. someone
   b. someone s/he lives with
   c. someone s/he works with
   d. someone s/he has non-penetrative sex with
   e. someone s/he has penetrative sex with
   f. her/his physician
   g. her/his dentist

2. Parent(s) of an HIV seropositive child need to tell:

   a. child's school principal
   b. child's main teacher
   c. child's babysitter
   d. child's day care worker

Then discuss reactions to answering questions about who should be told about HIV seropositivity.

SHARING INFORMATION ABOUT HIV+ STATUS

1. Do you want to tell someone?

2. If yes, who and why?

3. What are the positive and negative reasons for disclosing?

4. What exact words would you say? (Practice and rehearse)

5. What are the possible positive and negative reactions of that person?

6. What would you feel/do about each of those (supra)possibilities? What's your plan?

7. Would you feel more/less comfortable with a facilitator present?

8. If you ever decided to tell someone, who would you choose?Why?

9. Is there any other way I can help?

ESSENTIALS OF PRE-TEST COUNSELING (PRE)

Privacy and confidentiality

"Anything you tell me is confidential. There is an anonymous testing site in the Health Department."

Risk assessment and risk reduction

"These are activities that put you at risk for HIV infection. If you're thinking of having similar experiences then we'll have to talk about ways that you can protect yourself."

Explanation of the test for informed consent

"Let me describe the HIV antibody test. You don't have to take the test if you don't want to."

Common Pitfalls in Pre-Test Counseling

* closed questions ("Are you married?" "Do you use drugs?")
* negative labels ("No homosexual contact, right?")
* assumptions about risk status (You're not in the high- risk group for AIDS.")

ESSENTIALS OF POST-TEST COUNSELING (POST)

Privacy and confidentiality of test results

"In general, it's not necessary to tell anyone except those people you could pass the virus to, such as sex partners."

Optimism in discussing results

"There are some promising experimental treatments and there are ways to keep your immune system strong."

Support system and suicide risk assessment

"Will you be okay in the meantime? Some people get very upset and consider hurting themselves."

Transmission issues and partner notification

"Do you have any questions about how to have safer sex? If you've been sexually active with or without protection it's important that she [he, they] be counseled."

Common Pitfalls in Post-Test Counseling

* failing to wait for test confirmation before discussing results
* failing to explain the difference between HIV seropositivity and the disease AIDS

- failing to assess patient's emotional status and support systems
- failing to counsel about risk reduction and partner notification

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CENTERS FOR DISEASE CONTROL

August 14, 1987 / Vol. 36 / No. 31

MMWR

MORBIDITY AND MORTALITY WEEKLY REPORT

509 PHS Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS
515 Polymer-Fume Fever Associated with Cigarette Smoking and the Use of Tetrafluoroethylene – Mississippi
522 Update: AIDS – United States
526 Publication of Revised Case Definition for AIDS Surveillance
526 Regional Scientific Meeting of IEA, ICEN, and FETPs – January 24-29, 1988, Pattaya, Thailand

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Perspectives in Disease Prevention and Health Promotion

Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS

These guidelines are the outgrowth of the 1986 recommendations published in the *MMWR* (*1*); the report on the February 24-25, 1987, Conference on Counseling and Testing (*2*); and a series of meetings with representatives from the Association of State and Territorial Health Officials, the Association of State and Territorial Public Health Laboratory Directors, the Council of State and Territorial Epidemiologists, the National Association of County Health Officials, the United States Conference of Local Health Officers, and the National Association of State Alcohol and Drug Abuse Directors.

Human immunodeficiency virus (HIV), the causative agent of acquired immunodeficiency syndrome (AIDS) and related clinical manifestations, has been shown to be spread by sexual contact; by parenteral exposure to blood (most often through intravenous [IV] drug abuse) and, rarely, by other exposures to blood; and from an infected woman to her fetus or infant.

Persons exposed to HIV usually develop detectable levels of antibody against the virus within 6-12 weeks of infection. The presence of antibody indicates current infection, though many infected persons may have minimal or no clinical evidence of disease for years. Counseling and testing persons who are infected or at risk for acquiring HIV infection is an important component of prevention strategy (*1*). Most of the estimated 1.0 to 1.5 million infected persons in the United States are unaware that they are infected with HIV. The primary public health purposes of counseling and testing are to help uninfected individuals initiate and sustain behavioral changes that reduce their risk of becoming infected and to assist infected individuals in avoiding infecting others.

Along with the potential personal, medical, and public health benefits of testing for HIV antibody, public health agencies must be concerned about actions that will discourage the use of counseling and testing facilities, most notably the unauthorized disclosure of personal information and the possibility of inappropriate discrimination.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES / PUBLIC HEALTH SERVICE

Guidelines – Continued

Priorities for public health counseling and testing should be based upon providing ready access to persons who are most likely to be infected or who practice high-risk behaviors, thereby helping to reduce further spread of infection. There are other considerations for determining testing priorities, including the likely effectiveness of preventing the spread of infection among persons who would not otherwise realize that they are at risk. Knowledge of the prevalence of HIV infection in different populations is useful in determining the most efficient and effective locations providing such services. For example, programs that offer counseling and testing to homosexual men, IV-drug abusers, persons with hemophilia, sexual and/or needle-sharing partners of these persons, and patients of sexually transmitted disease clinics may be most effective since persons in these groups are at high risk for infection. After counseling and testing are effectively implemented in settings of high and moderate prevalence, consideration should be given to establishing programs in settings of lower prevalence.

Interpretation of HIV-Antibody Test Results

A test for HIV antibody is considered positive when a sequence of tests, starting with a repeatedly reactive enzyme immunoassay (EIA) and including an additional, more specific assay, such as a Western blot, are consistently reactive.

The *sensitivity* of the currently licensed EIA tests is 99% or greater when performed under optimal laboratory conditions. Given this performance, the probability of a false-negative test result is remote, except during the first weeks after infection, before antibody is detectable.

The *specificity* of the currently licensed EIA tests is approximately 99% when repeatedly reactive tests are considered. Repeat testing of specimens initially reactive by EIA is required to reduce the likelihood of false-positive test results due to laboratory error. To further increase the specificity of the testing process, laboratories must use a supplemental test—most often the Western blot test—to validate repeatedly reactive EIA results. The sensitivity of the licensed Western blot test is comparable to that of the EIA, and it is highly specific when strict criteria are used for interpretation. Under ideal circumstances, the probability that a testing sequence will be falsely positive in a population with a low rate of infection ranges from less than 1 in 100,000 (Minnesota Department of Health, unpublished data) to an estimated 5 in 100,000 (*3,4*). Laboratories using different Western blot reagents or other tests or using less stringent interpretive criteria may experience higher rates of false-positive results.

Laboratories should carefully guard against human errors, which are likely to be the most common source of false-positive test results. All laboratories should anticipate the need for assuring quality performance of tests for HIV antibody by training personnel, establishing quality controls, and participating in performance evaluation systems. Health department laboratories should facilitate the quality assurance of the performance of laboratories in their jurisdiction.

Guidelines – Continued

Guidelines for Counseling and Testing for HIV Antibody

These guidelines are based on public health considerations for HIV testing, including the principles of counseling before and after testing, confidentiality of personal information, and the understanding that a person may decline to be tested without being denied health care or other services, except where testing is required by law (*5*). Counseling before testing may not be practical when screening for HIV antibody is required. This is true for donors of blood, organs, and tissue; prisoners; and immigrants for whom testing is a Federal requirement as well as for persons admitted to state correctional institutions in states that require testing. When there is no counseling before testing, persons should be informed that testing for HIV antibody will be performed, that individual results will be kept confidential to the extent permitted by law, and that appropriate counseling will be offered. Individual counseling of those who are either HIV-antibody positive or at continuing risk for HIV infection is critical for reducing further transmission and for ensuring timely medical care.

Specific recommendations follow:

1. *Persons who may have sexually transmitted disease.* All persons seeking treatment for a sexually transmitted disease, in all health-care settings including the offices of private physicians, should be routinely* counseled and tested for HIV antibody.
2. *IV-drug abusers.* All persons seeking treatment for IV-drug abuse or having a history of IV-drug abuse should be routinely counseled and tested for HIV antibody. Medical professionals in all health-care settings, including prison clinics, should seek a history of IV-drug abuse from patients and should be aware of its implications for HIV infection. In addition, state and local health policy makers should address the following issues:
    - Treatment programs for IV-drug abusers should be sufficiently available to allow persons seeking assistance to enter promptly and be encouraged to alter the behavior that places them and others at risk for HIV infection.
    - Outreach programs for IV-drug abusers should be undertaken to increase their knowledge of AIDS and of ways to prevent HIV infection, to encourage them to obtain counseling and testing for HIV antibody, and to persuade them to be treated for substance abuse.
3. *Persons who consider themselves at risk.* All persons who consider themselves at risk for HIV infection should be counseled and offered testing for HIV antibody.

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*"Routine counseling and testing" is defined as a policy to provide these services to all clients after informing them that testing will be done. Except where testing is required by law, individuals have the right to decline to be tested without being denied health care or other services.

4. *Women of childbearing age.* All women of childbearing age with identifiable risks for HIV infection should be routinely counseled and tested for HIV antibody, regardless of the health-care setting. Each encounter between a health-care provider and a woman at risk and/or her sexual partners is an opportunity to reach them with information and education about AIDS and prevention of HIV infection. Women are at risk for HIV infection if they:
   - Have used IV drugs.
   - Have engaged in prostitution.
   - Have had sexual partners who are infected or are at risk for infection because they are bisexual or are IV-drug abusers or hemophiliacs.
   - Are living in communities or were born in countries where there is a known or suspected high prevalence of infection among women.
   - Received a transfusion before blood was being screened for HIV antibody but after HIV infection occurred in the United States (e.g., between 1978 and 1985).

   Educating and testing these women before they become pregnant allows them to avoid pregnancy and subsequent intrauterine perinatal infection of their infants (30%-50% of the infants born to HIV-infected women will also be infected).

   All pregnant women at risk for HIV infection should be routinely counseled and tested for HIV antibody. Identifying pregnant women with HIV infection as early in pregnancy as possible is important for ensuring appropriate medical care for these women; for planning medical care for their infants; and for providing counseling on family planning, future pregnancies, and the risk of sexual transmission of HIV to others.

   All women who seek family planning services and who are at risk for HIV infection should be routinely counseled about AIDS and HIV infection and tested for HIV antibody. Decisions about the need for counseling and testing programs in a community should be based on the best available estimates of the prevalence of HIV infection and the demographic variables of infection.

5. *Persons planning marriage.* All persons considering marriage should be given information about AIDS, HIV infection, and the availability of counseling and testing for HIV antibody. Decisions about instituting routine or mandatory premarital testing for HIV antibody should take into account the prevalence of HIV infection in the area and/or population group as well as other factors and should be based upon the likely cost-effectiveness of such testing in preventing further spread of infection. Premarital testing in an area with a prevalence of HIV infection as low as 0.1% may be justified if reaching an infected person through testing can prevent subsequent transmission to the spouse or prevent pregnancy in a woman who is infected.

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Guidelines – Continued

6. *Persons undergoing medical evaluation or treatment.* Testing for HIV antibody is a useful diagnostic tool for evaluating patients with selected clinical signs and symptoms such as generalized lymphadenopathy; unexplained dementia; chronic, unexplained fever or diarrhea; unexplained weight loss; or diseases such as tuberculosis as well as sexually transmitted diseases, generalized herpes, and chronic candidiasis.

   Since persons infected with both HIV and the tubercle bacillus are at high risk for severe clinical tuberculosis, all patients with tuberculosis should be routinely counseled and tested for HIV antibody (*6*). Guidelines for managing patients with both HIV and tuberculous infection have been published (*7*).

   The risk of HIV infection from transfusions of blood or blood components from 1978-1985 was greatest for persons receiving large numbers of units of blood collected from areas with high incidences of AIDS. Persons who have this increased risk should be counseled about the potential risk of HIV infection and should be offered antibody testing (*8*).
7. *Persons admitted to hospitals.* Hospitals, in conjunction with state and local health departments, should periodically determine the prevalence of HIV infections in the age groups at highest risk for infection. Consideration should be given to routine testing in those age groups deemed to have a high prevalence of HIV infection.
8. *Persons in correctional systems.* Correctional systems should study the best means of implementing programs for counseling inmates about HIV infection and for testing them for such infection at admission and discharge from the system. In particular, they should examine the usefulness of these programs in preventing further transmission of HIV infection and the impact of the testing programs on both the inmates and the correctional system (*9*). Federal prisons have been instructed to test all prisoners when they enter and leave the prison system.
9. *Prostitutes.* Male and female prostitutes should be counseled and tested and made aware of the risks of HIV infection to themselves and others. Particularly prostitutes who are HIV-antibody positive should be instructed to discontinue the practice of prostitution. Local or state jurisdictions should adopt procedures to assure that these instructions are followed.

Partner Notification/Contact Tracing

Sexual partners and those who share needles with HIV-infected persons are at risk for HIV infection and should be routinely counseled and tested for HIV antibody. Persons who are HIV-antibody positive should be instructed in how to notify their partners and to refer them for counseling and testing. If they are unwilling to notify their partners or if it cannot be assured that their partners will seek counseling, physicians or health department personnel should use confidential procedures to assure that the partners are notified.

Guidelines – Continued

Confidentiality and Antidiscrimination Considerations

The ability of health departments, hospitals, and other health-care providers and institutions to assure confidentiality of patient information and the public's confidence in that ability are crucial to efforts to increase the number of persons being counseled and tested for HIV infection. Moreover, to assure broad participation in the counseling and testing programs, it is of equal or greater importance that the public perceive that persons found to be positive will not be subject to inappropriate discrimination.

Every reasonable effort should be made to improve confidentiality of test results. The confidentiality of related records can be improved by a careful review of actual record-keeping practices and by assessing the degree to which these records can be protected under applicable state laws. State laws should be examined and strengthened when found necessary. Because of the wide scope of "need-to-know" situations, because of the possibility of inappropriate disclosures, and because of established authorization procedures for releasing records, it is recognized that there is no perfect solution to confidentiality problems in all situations. Whether disclosures of HIV-testing information are deliberate, inadvertent, or simply unavoidable, public health policy needs to carefully consider ways to reduce the harmful impact of such disclosures.

Public health prevention policy to reduce the transmission of HIV infection can be furthered by an expanded program of counseling and testing for HIV antibody, but the extent to which these programs are successful depends on the level of participation. Persons are more likely to participate in counseling and testing programs if they believe that they will not experience negative consequences in areas such as employment, school admission, housing, and medical services should they test positive. There is no known medical reason to avoid an infected person in these and ordinary social situations since the cumulative evidence is strong that HIV infection is not spread through casual contact. It is essential to the success of counseling and testing programs that persons who are tested for HIV are not subjected to inappropriate discrimination.

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Polymer-Fume Fever Associated with Cigarette Smoking and the Use of Tetrafluoroethylene – Mississippi

Three of the five workers at a Mississippi shop that produces plastic signs and rubber and metal stamps had several episodes of severe "flu-like" symptoms between July 1985 and March 1986. The symptoms were of unknown origin and usually subsided within a day. Only the employees making stamps were affected. In response to a request by the company's owner, the National Institute for Occupational Safety and Health (NIOSH) sent a medical officer and an industrial hygienist to investigate on March 4, 1986.

The investigators observed work processes, reviewed material safety data sheets to determine the composition of materials being used, and recorded the affected employees' medical histories. They also collected ambient air samples to test for various solvents and metal fumes. These tests showed no detectable levels of trace metals and only trace (microgram) amounts of xylene, toluene, methyl chloroform, and hexane, all of which were well below the respective exposure levels recommended by NIOSH.

The investigators learned, however, that there had been a change in the stamp-making process during the summer of 1985. Prior to that time, a phenolic mold board had been used during production of rubber stamps and notary seals. In early July 1985, the company's supplier had switched to an asbestos-free board. In making the stamps, a die is heat-pressed into the board in a small oven at 152 C (305 F) for about 20 minutes. The die is then used to mold a rubber sheet into the stamp's image. Because this new composition board did not release the rubber sheet properly, a mold-release spray was used.

The material safety data sheet for the mold-release spray indicated the presence of a small amount (<1%) of tetrafluoroethylene, a fluorocarbon monomer. It also warned that fluorocarbon propellants could pose a public health problem by reducing ozone in the upper atmosphere and that excessive heating might burst the container. The supplier failed to state that the products of decomposition of fluorocarbon monomers and polymers can produce a condition known as "polymer-fume fever" and that cigarette smoking is the most common means of creating exposure to these products.

FOCUS A REVIEW OF AIDS RESEARCH

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AIDS-Related Suicide: A Dilemma for Health Care Providers

Peter Goldblum, PhD and
Jeffrey Moulton, PhD

Suicide among people with AIDS thrusts upon everyone involved serious philosophical, legal, and ethical dilemmas. Health professionals often find that these profound questions of life, death, and choice disrupt their sense of professional obligations and force a review of moral responsibilities and legal restrictions.

Suicide is an especially pertinent issue in AIDS because of the profound and progressive nature of the disease, the seeming unchangeability of the condition, and the often painful and disfiguring deterioration that occurs. These factors may place thousands of people — from those with evidence of HIV infection to those with AIDS clinical disease — at particularly high risk for despair and hopelessness and thus at eventual risk for suicide. As the incidence of AIDS has risen, health care professionals have found themselves becoming involved with increasing numbers of clients with suicide-related concerns.

The Extent of the Problem

The scope of the suicidal ideation, attempts, and completed suicides among people with AIDS is unknown due to the lack of epidemiological data. However, the numerous anecdotal reports from across the United States and the limited record-keeping by San Francisco agencies indicate that suicide is, indeed, a salient issue in AIDS. Hospice of San Francisco has documented thirteen suicide attempts and six completed suicides in persons with AIDS from October 1984 to April 1986. In a recent six-week period (February-March 1986), the Shanti Project identified eleven persons with serious suicidal ideation, seven suicide attempts, and one completed suicide. The San Francisco Medical Examiner estimated that six to twelve persons with AIDS committed suicide in 1985. Since suicides are difficult to detect, this number may be low. The Tenderloin Outpatient Mental Health Clinic also reported that of the eight persons with AIDS and fourteen persons with ARC seen there, three had attempted suicide. In addition, the San Francisco Suicide Prevention Center reported that it receives 60 to 100 AIDS-related telephone calls per month.

While these numbers in no way reveal the extent of suicide in persons with AIDS-related health problems, they do indicate that it is likely that practitioners will be confronted by the many issues related to suicide in working with these individuals. Although the large urban centers with high numbers of AIDS cases may also have larger numbers of suicide-related problems, it is likely that similar problems exist in smaller communities. The possibly greater isolation and limited support services for people with AIDS in smaller cities may contribute to suicide behavior.

Definitions and Distinctions

AIDS-related suicide behavior is a specifically defined term which delimits the problem. Suicide behavior includes suicidal thoughts, suicide attempts, and completed suicides. Suicide attempts range from efforts by those with a high intention to kill themselves to those whose aim is other than self-destruction, for example, a cry for help. The term AIDS-Related refers to the whole range of AIDS concerns for those who are diagnosed with AIDS or ARC, those who are experiencing grief related to AIDS, people who have concerns related to their antibody status, and generally anyone who has concerns related to contracting the disease.

> *"Clinicians must be especially careful to maintain confidentiality when dealing with people who have AIDS-related concerns. This issue is made more difficult at times when people are assessed imminently to be a danger to themselves. At such a point their safety supersedes their rights of confidentiality."*

The Euthanasia Society has defined Rational Suicide as a suicide in which the mental processes leading to the decision to commit suicide are unimpaired by psychological illness or severe emotional distress. Also, the motivational basis of the decision would be understandable to the majority of the person's peer group. For example, an individual may seek consultation about how to complete a suicide when the pain and deterioration have increased beyond the point of endurance. Thus, rational suicides can be compared with suicides in which the mental processes of the individual are clouded.

Responsibility of the Clinician

The basic premise of this discussion is that a clinician must understand and balance a person's right to competent professional psychological care with the right to die with dignity. With this in mind, the first responsibility for clinicians who counsel people considering suicide is to understand clearly what has led to their clients' suicidal thinking. The clinician must identify whether reasons exist for the person's thinking to be clouded. By helping clients clarify their thoughts and feelings, more satisfactory options may be developed. For people who continue to seriously consider suicide after carefully examining the issues, the clinician must consider taking more active measures, such as psychotropic medication or involuntary hospitalization.

continued on page 2

THE AIDS HEALTH PROJECT

A Publication of the AIDS Health Project University of California San Francisco

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AIDS-related suicide...

continued from cover

The law in the United States clearly disallows clinicians from aiding and abetting a person to commit suicide. Individual states address this issue differently. For example, in California the Welfare and Institutions Code provides specific conditions under which the health provider is required to intervene to prevent suicide, i.e., if a person is judged to be a danger to self due to "mental disorder or defect." Under these circumstances the clinician must admit the person for psychiatric hospitalization — even if this is against the person's wishes.

Difficult questions arise throughout the counseling process of suicidal clients. Some of the difficulty lies in the realm of clinical judgment: "Are the individuals truly a danger to themselves?" Vagueness in psychological theory and practice may also make decisions difficult: "What is meant by mental disorder or defect? Is suicidal thinking by itself an indication of psychological illness?" Other questions are more philosophical and ethical in nature: "Are there ever situations in which clinicians can agree with their clients that they are better off dead?" In other words, are there rational suicides? If so, what is the clinician's responsibility — a passive stance of noninterference or a more active stance of assisting? What are the limits of this assistance?

Legal Issues

Health professionals should consider three legal concerns to help determine their clinical responsibilities toward clients who are considering taking their own lives: (1) malpractice, (2) aiding and abetting, and (3) the need to hospitalize or detain people on an involuntary basis.

Malpractice. In terms of malpractice, the courts have taken a realistic view of the uncertainties inherent in clinical science. To avoid liability, the practitioner does not have to be proven "right" by the outcome. But clinicians have been found liable for defective clinical reasoning; for example, for the failure to recognize the risk of suicide and for underestimating the seriousness of the risk and for not taking the precautions needed to counter it. Burszatjn, Grutheil, Hamm, and Brodsky [1] have outlined three standards by which possible negligence can be evaluated: (1) community standard, (2) maximization of benefits relative to costs, and (3) reasonable and prudent practitioner.

Community standard means that clinicians have exercised due care if they have done what others in the relevant professional community would do in a similar circumstance. Maximization of benefits to costs is a way to understand the complexity of decisions on the part of the clinician in order to prevent a client from committing suicide. The decision to hospitalize a client (voluntarily or involuntarily), to place a patient under closer observation and restraint in the hospital, or to discharge a patient is a complex one requiring the clinician to balance a host of possible costs and benefits. What is known as the "Learned Hand Rule" holds that negligent behavior represents the failure to invest resources up to a level that is equal to the anticipated savings in damages. The courts do recognize, however, that no amount of precautions can give absolute assurance that the patient will not commit suicide. The question here is "Could the clinician 'reasonably' have been expected to foresee the likelihood of a completed suicide or suicide attempt or taken greater precautions to prevent it?"

Aiding and abetting. Although it is not illegal to commit suicide, some state laws (such as those in California) clearly forbid aiding and abetting. This applies to everyone, not only health professionals. Such forbidden activities might include providing the actual means for committing suicide or actively encouraging a client to undertake a suicide. Aiding and abetting is considered a felony. Furthermore, health care providers cannot tell patients how to commit suicide. Informing someone about the Hemlock Society, by itself, would probably not constitute aiding and abetting. The courts would probably look on this in light of other actions taken by the practitioner.

Decision to hospitalize. When deciding whether to hospitalize or detain people on an involuntary basis, the clinician must balance overreacting (taking unnecessary restrictive actions to protect the client from himself) and underreacting (no taking appropriate measures to protect the individual). Paramount issues related to balancing legal responsibility involve protecting the client from self-harm and the rights of clients not to be unjustifiably incarcerated.

A legal requirement for the clinician working with a suicidal client is that of informed consent. Informed consent is the discussion of treatment options with the client, such as antidepressant medication and hospitalization, including the possible negative side-effects of each.

Clinicians must be especially careful to maintain confidentiality when dealing with people who have AIDS-related concerns. The possible damage to a person is considerable given the hysteria and possible reprisals connected with AIDS. This issue is made more difficult at times when people are assessed to be imminently a danger to themselves. At such a point their safety supersedes their rights of confidentiality.

The conclusions of Burszatjn, Grutheil, Hamm, et al. are relevant to these AIDS and suicide issues: (1) clinicians should feel reassured by recent court decisions which demonstrate a congruence between clinical and legal standards; (2) clinicians need to understand legal standards of negligence and informed consent; (3) clinicians are best safeguarded from malpractice suits by careful documentation of both objective information and subjective information; (4) clinicians need to review treatment options with clients and document the process of informed consent for treatment; (5) clinicians should request and document consultation in cases where action on the part of the clinician can be misconstrued.

Summary. Suicide issues are always difficult for the health care worker; the controversial social and political nature of AIDS only compounds the difficulties. Yet this complex issue is one that is likely to confront practitioners in increasing frequency as the number of people affected by AIDS continues to increase dramatically. An understanding of the ethical and legal concerns involved can help alleviate some of the uncertainty and distress for health care providers who cope with this emotionally-charged issue.

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Diagnosis / Treatment

Suicide: Clinical Aspects

Peter Goldblum, PhD

To provide competent clinical services to people with AIDS-related suicide behaviors, the clinician must be aware of basic suicide interventions and be adept in applying them to the more specific AIDS issues involved. The following discussion highlights clinical insights[1] derived from working with people wh experience the full range of AIDS concerns.

Countertransference

Emotional issues surrounding AIDS may cloud clinicians' judgment. Clinicians unfamiliar with working with medically ill [illegible] may feel overwhelmed by the pertinent medical information and terminology. Clinicians may also be affected by several countertransference responses. These include the following:

1. Clinicians should recognize their own reactions and biases when working with people who have suicidal thoughts related to AIDS.
2. Clinicians must face their own death anxiety. The uncertainty regarding the course of the illness may be unsettling to clinicians as well as to clients.
3. Clinicians must balance overreacting (taking unnecessarily restrictive actions to protect clients from themselves) and underreacting (not taking appropriate measures to protect clients).
4. Clients with long histories of unsuccessful involvement in the mental health system (especially those with severe personality disorders) may prompt clinician reactions that can cloud their judgment in assessing these clients' suicide risk.

General Suicide Assessment. In assessing the suicide potential of a person with AIDS-related concerns, the first step is to consider standard risk factors for suicide: depression, recent loss, substance abuse, age, sex, current stressors, prior suicidal behavior, current plan, resources, and support system.

Risk Factors for Suicide in Other Life-Threatening Diseases. Risk factors for suicide that have been identified in patients with other life-threatening diseases may be helpful in alerting health providers to suicide risk among people with AIDS.

Faberow[2] found distinctive psychosocial differences between terminally ill cancer patients who committed suicide and a control group of terminally ill cancer patients who did not commit suicide but who died from their disease. Characteristics of those who committed suicide are summarized below:

1. emotional stress over and above the physiological aspects of the disease;
2. exhaustion of physical and emotional resources (including a feeling of lack of family and hospital support);
3. prior suicide attempts;
4. significantly more complaints of pain and discomfort;
5. near-death physical condition;
6. alcoholism and drug abuse involvement.

Specific Risk Factors for People with AIDS-Related Concerns. There have been no formal studies to determine if there are factors which specifically place a person with AIDS-related concerns at risk for suicide. However, the following represent possible risk factors gleaned from clinical insight (These observations pertain mostly to working with gay men):

1. multiple losses related to AIDS — either deaths or illnesses of friends or lovers; or other losses, such as employment or housing;
2. intimate involvement with another person who has died of AIDS (This past experience often has a decided impact on people as they enter the final stages of their own illness);
3. different stages of the disease may pose different risks of suicide and personal needs may change as the illnesses progress;
   (a). **The Recently-Diagnosed Stage** — The person may have a lack of information related to the course and nature of the disease and may not understand the resources that are available.
   (b). **The Midstage** — At this stage a person's defenses may begin to break down and thoughts of death and suffering may intrude the consciousness.
   (c). **The Final Stage** — At this stage clients confront increased issues of dependency, pain, and loss of control of bodily functions.
4. great anxiety for people with ARC who are uncertain of their health status and their future, find their life planning disrupted, experience a loss of physical stamina, and enjoy little of the special "status" given to those with AIDS;
5. recent notification of a positive result from the AIDS antibody test;
6. discrimination, insults, or injury due to fear of AIDS or homophobia;
7. personal histories of losses related to homophobia (family history of rejection, history of employment or legal problems related to being gay);
8. a prevailing attitude that "the world is a dangerous place to be gay" and subsequent suspiciousness and anger toward non-gays;
9. remaining in "the closet," that is, taking part in homosexual behavior but avoiding identification with the gay community and thus often experiencing guilt and personal conflict;
10. an unsettled sexual identity, especially experienced by adolescents who feel that they may be gay;
11. lack of a social and financial support system that is adequate for coping with the AIDS epidemic.

Personality Factors

Personality factors play an important role in how people cope with the full range of AIDS concerns. Segal and Tuckel[3] suggest that a person's psychological make-up is more important than any particular disease in affecting the suicidal or nonsuicidal outcome for a person coping with terminal illness.

People with severe personality problems may be blocked in their access to services due to their manipulative behavior and management problems.

Jerome Motto[4] proposed a classification scheme of two distinct categories of people at risk for committing suicide. The two models are (1) those who are "stable and experience a forced change" and (2) those who are chronically "alienated." The first group commit suicide after a significant loss or threatened loss. These individuals have a "high" rating for overall stability or prior life patterns. The "alienated" group, on the other hand, experiences suicidal ideas extending over years or a lifetime. They have chronically low self-esteem. These people may commit suicide without an apparent significant loss.

Clinical Interventions

The following clinical issues are important in working with people with AIDS-related suicide concerns.

1. Develop a good working alliance. Blocks to the alliance must be understood and worked through. If blocks cannot be overcome, the client should be referred to another mental health provider.
2. Clients with AIDS-related concerns come from a broad spectrum of racial, cultural, and sexual backgrounds.
3. Discussion of suicidal thoughts should be initiated early. Given the progressive, deteriorating nature of the disease, suicidal clients may plan their suicide many weeks in advance for when "the time comes." The final act may follow a change in health status, which may "trigger" the suicide.
4. Wherever possible, patients should be allowed choices and be given an active role in their treatment. People with AIDS and ARC may think of suicide as a means of having a measure of control over their lives.
5. Cognitive approaches to depression and hopelessness have been found to be useful tools. Beck[4] has emphasized the importance of perceived hopelessness in suicidal potential. Efforts to help clients derive a measure of hope in the crisis is important.
6. Clinical assistance to support networks (lovers, friends, family) should be made available. People with AIDS moving into the final stage of the illness may commit suicide as an altruistic act to protect loved ones from protracted suffering.

continued on page 4

7. Suicidal thoughts may be an expression of anger directed at people in the immediate support system or the larger system. Encouragement of expression of feelings is an important starting point.
8. Suicidal thoughts may accompany the loss of physical attractiveness and changes in body image. These concerns must be taken seriously and the mourning of these losses validated.
9. Issues of blame and guilt are very complicated for people with AIDS-related concerns. Issues of internalized homophobia are particularly important in determining how gay people cope with AIDS concerns. It is important to allow people to express negative thoughts and feelings and then discuss how they want to relate to them.

Summary. Clinical services offered to people with AIDS and AIDS-related complaints may well ease the distress associated with concerns about suicide. Most people with AIDS and related health problems do not attempt to commit suicide. However, thoughts about taking one's own life are likely to accompany any life-threatening illness.

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BRIEFS

IN REVIEW

Night Kites by M. E. Kerr, Harper & Row Junior Books, New York, 1986; 210 pages, hardbound, $11.50.

Although the author can be complimented for introducing AIDS to the teen audience, this novel is not great literature. It cannot compare with the grace and style of the novels of, say, J. D. Salinger or Rosa Guy. The teen characters, all from a privileged white suburb of New York City, seem overly interested in the latest designer jeans, and the constant reference to current rock music groups is an irritating intrusion into the plot.

Even with these limitations, "Night Kites" is still an important contribution to juvenile literature. The characters cope with realistic problems and, like real teenagers (and adults), they are often clumsy in their solutions. They have faults. They have fights. They have feelings. They have sex.

When protagonist Erick's older brother Pete returns home diagnosed with AIDS, members of the family deal with their own fears and prejudices as well as the judgments of others, with varying levels of success. There are no miracle cures in this novel and no Hollywood ending. Readers do get a real sense of Erick's growth and grief — and his own type of personal triumph — by the novel's end.

AIDS educators, social workers, and other health professionals can appreciate the lack of popular literature that addresses AIDS in a realistic manner. This recent entry into the teen reading market helps demystify the health crisis, and may lessen the fear and isolation felt by young people who encounter AIDS in their circles of friends and family.

— Reviewed by **Marcia Quackenbush, MS, MFCC,**
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RECENT REPORTS

Women with AIDS: A Comparison of Sex Differences. Women from the non-I.V. drug user ("other") category were diagnose with AIDS later and entered hospitals for initial treatment at higher level of illness severity than patients from all othe comparison groups, according to a study conducted in New York City. Joanne E. Mantell and her colleagues at St. Luke's/Roosevelt Hospital Center and New York Medical College also found that female patients had the longest average length of hospital stay. The study looked at sex differences in diagnosis, illness severity, treatment, hospitalization needs, and sociodemographic data.

These women also had the least amount of body system involvement in their illness and expressed the fewest number of suicidal threats. In sharp contrast to four-fifths of the male subjects, only one-half of female patients exhibited at least one form of neuropsychiatric behavioral problems that interfered with treatment. The researchers commented that "this finding might suggest that CNS [central nervous system] involvement manifests differently in women as compared to men, or that women exhibit more compliant behaviors during hospitalization." Researcher Mantell and her colleagues advised that caregivers should consider the reasons for women's apparent delay in seeking medical care. They also suggested that the problems of women with AIDS, such as care of dependent children after their mothers' deaths, merited special attention. The New York researchers presented their findings during the International Conference on AIDS in Paris.

The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. This newsletter represents an attempt to place much of the data and press reports in a context tha will prove meaningful and useful to its readers. Suggestions and comments are welcome and encouraged. Please address correspondence to Editor, AIDS Health Project; 333 Valencia Street, 4th Floor; San Francisco, CA 94103. For information about the other AIDS Health Project programs, call (415) 626-6637.

NEXT MONTH

Health care professionals are well aware that the public perception of AIDS affects every aspect of their work — from patient care and hospital policies to education and service delivery. Public attitudes about contagion, new therapies, levels of research funding, homosexuality, and I.V. drug use are frequently gauged and monitored by national polls. In the December issue of FOCUS, Stephen Mills, doctoral candidate in communication at the University of Michigan and research analyst at SRI International in Menlo Park, California will look at the trends and changes in the public perception of AIDS during the last five years.

In addition, medical specialists from San Francisco General Hospital will discuss the management of psychiatric patients with AIDS on an inpatient psychiatric ward. Jay Baer, MD, Susan Lewitter Koehler, RN, MS, and Kris Holm, RN will consider the difficulties with patient disposition, symptom management, the kinds of patients being seen, and the rate of increase of psychiatric patients on Ward 7B, the hospital inpatient unit for psychiatric AIDS patients. Baer is the attending physician on Ward 7B; Holm is the acting head nurse; and Lewitter Koehler is a clinical nurse specialist.

Original Contributions

Increased Risk of Suicide in Persons With AIDS

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The rate of suicide has been reported to be higher in persons with chronic and life-threatening illnesses (eg, cancer, Huntington's disease, and renal failure). We studied the rate of suicide in 1985 in New York City residents diagnosed with the acquired immunodeficiency syndrome (AIDS). There were 668 suicides in New York City residents in 1985, yielding a rate of 9.29 per 100 000 person-years. In men aged 20 to 59 years without a known diagnosis of AIDS, the rate was 18.75 per 100 000 person-years. There were 3828 individuals who lived with the diagnosis of AIDS for some part, or all, of 1985. There were 12 suicides in men aged 20 to 59 years from this group who lived 1763.25 person-years with a diagnosis of AIDS. This yields a suicide rate of 680.56 per 100 000 person-years. Thus, the relative risk of suicide in men with AIDS aged 20 to 59 years was 36.30 times (95% confidence limits, 20.45 to 64.42) that of men aged 20 to 59 years without this diagnosis, and 66.15 times (95% confidence limits, 37.38 to 117.06) that of the general population. We conclude that AIDS represents a significant risk factor for suicide.

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A NUMBER of studies have found a higher risk of suicide among persons with selected underlying medical illnesses than that of the general population. For example, the suicide rate among patients with chronic renal disease undergoing dialysis has been estimated at ten to 50 times greater than that of the general population.[1,2] In patients with Huntington's disease, the proportion who die by suicide is three to 23 times that found in the general population.[3,4] Suicide rates among cancer patients are elevated only modestly (one to four times) compared with the general population.[5-8] Some of the highest rates of suicide occur in patients who have mental illnesses—ten to 80 times that of the general population.[9] The Iowa Record Linkage Study recorded increased rates among persons with schizophrenia, affective disorders, alcohol abuse and drug use, as well as increased rates for males with organic mental disorders within the first two years after diagnosis.[9-11]

For editorial comment see p 1369.

Despite the fact that a number of studies report that the acquired immunodeficiency syndrome (AIDS) is associated with a range of psychiatric syndromes (including depression, paranoia, psychoses, dementia, and delirium[12-14]), it has been suggested, anecdotally, that while AIDS patients have suicidal ideation, the risk of actual suicide attempts is low.[14] However, no published studies have addressed this question directly. We present evidence herein demonstrating that the rate of suicide in persons with AIDS is substantially higher than equivalent age- and gender-specific rates of the general population.

METHODS

Determination of Suicide

Data were collected by reviewing all cases of suicide in New York City, as coded by the Office of Biostatistics, New York City Department of Health. All cases of suicide were certified as such by the Office of Chief Medical Examiner of the City of New York. Only suicides among New York City residents occurring from Jan 1, 1985, through Dec 31, 1985, were included in the data analysis.

In determining that the manner of death was suicide, the medical examiner must ascertain that a cause of death involved the possibility of self-inflicted injuries. Furthermore, an investigation may reveal additional evidence (eg, circumstances of death indicating self-destruction, history of despondency, prior psychiatric treatment, or presence of a suicide note) that would support a certification of suicide. While no single combination of evidence invariably leads to a determination of death as suicide, certain combinations are more likely to result in a determination of suicide than others. When the cause of death involves the possibility of self-inflicted injuries, but additional evi-

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Table 1.—Age-Specific Suicide Rates Among Males Diagnosed With AIDS* and Among Males in the General Population: 1985†

Age Group, y	No. of Males Diagnosed With AIDS Living ≥1 d in 1985	Person-Years of Life With AIDS in 1985‡	No. of Suicides Among Males Diagnosed With AIDS	Rate of Suicide Among Males Diagnosed With AIDS§	Rate of Suicide Among Males in General Population‖	Relative Risk
10-19	5	3.2	0	...	2.89	...
20-24	91	43.5	1	2298.85	18.32	125.48
25-29	481	264.8	0	...	21.74	...
30-34	851	465.1	4	860.03	18.79	45.77
35-39	858	440.1	2	454.44	18.80	24.17
40-44	544	271.4	4	1473.84	15.97	92.29
45-49	301	147.7	0	...	21.40	...
50-54	190	89.5	0	...	20.25	...
55-59	102	41.1	1	2433.09	13.54	179.70
60-64	34	16.6	0	...	18.53	...
65-69	15	3.4	0	...	17.09	...
70-74	1	0.0	0	...	9.87	...
75-79	0	0.0	0	...	21.32	...
80-84	1	0.2	0	...	57.92	...
85+	1	0.5	0	...	20.94	...
Overall Total or Rate	3475	1787.1	12	671.40	16.42	40.89

*AIDS indicates the acquired immunodeficiency syndrome.
†New York City residents only.
‡From the AIDS Surveillance Unit, New York City Department of Health.
§Per 100 000 person-years of life with AIDS, 1985.
‖Per 100 000 person-years; 1985 midyear population based on projections from New York State Department of Commerce.

Table 2.—Suicide Rates Among Men Aged 20 to 59 Years Diagnosed With AIDS* and Among Men in the General Population: 1985†

	Suicide Category	
Variable	Cases Diagnosed With AIDS	Cases With No Diagnosis of AIDS
No. of suicides	12	349
Person-years of life	1763.25‡	1 860 856
Rates of suicide§	680.56	18.75
Relative risk	36.30	1.0
95% Confidence limits of relative risk‖	20.45-64.42	...

*AIDS indicates the acquired immunodeficiency syndrome.
†New York City residents only.
‡Person-years of life in 1985 after the diagnosis of AIDS.
§Per 100 000 person-years.
‖Confidence limits are estimated by calculating the interval in logarithmic scale and then taking antilogarithms.

dence indicating the circumstances or motives of the individual is lacking, the medical examiner may classify the manner of death as "undetermined." In all cases, the final determination is the judgment of the medical examiner. There were 567 deaths among New York City residents in 1985 in which the cause of death was established, but in which the manner of death was classified as undetermined. These deaths were excluded from this study.

The following sources of information were available: autopsy and toxicologic reports, results of police investigations, family member interviews by medical examiner staff or police at the time of death, and interviews with treating physicians contacted by medical examiners.

Determination of AIDS

Two methods were used to identify certified suicide cases of persons diagnosed with AIDS. One method relied on information contained in medical examiner records. The determination was based on medical record content, including details from reports of treating physicians (eg, several deaths occurred in hospitals), interviews with family members, autopsy evidence, police reports, and review of suicide notes where applicable. In the second method, the AIDS Surveillance Unit (New York City Department of Health) crossmatched registry information with a 1985 suicide list generated by the Biostatistics Division of the New York City Department of Health.

Calculation of the Rate of Suicide Among the General Population

Age-specific suicide rates for male and female residents of the five boroughs of New York City in 1985 were calculated by quinary cohorts aged 10 through at least 85 years. The rates were based on 1985 midyear population projections provided by the New York State Department of Commerce.[15] Each person in the general population was assumed to be at risk for suicide throughout the entire calendar year 1985, and thus contributed "one person-year at risk." Therefore, the rates of suicide were expressed per 100 000 person-years. As no suicides were reported among persons younger than 10 years, the population base used to calculate the overall suicide rate excluded children in this age group. No adjustment to the population base was made for months at risk lost by persons who committed suicide during 1985. Likewise, the contribution of time made by persons diagnosed with AIDS was not eliminated. In both instances, it was assumed that the correction factor would be smaller than any error associated with the projected 1985 midyear general population of New York City based on 1980 census counts.

Calculation of the Rate of Suicide Among Diagnosed AIDS Cases

Information concerning the incidence, prevalence, demographic characteristics, survival rates, and duration of illness of individuals with AIDS was provided by the AIDS Surveillance Unit of the New York City Department of Health. In calculating the suicide rate, only New York City residents who were diagnosed with AIDS were included; persons who lived elsewhere but diagnosed in New York City were excluded.

Persons diagnosed with AIDS before Jan 1, 1985, may have survived throughout 1985 or died after living only a portion of the year. Persons diagnosed with AIDS after or on Jan 1, 1985, may have survived the entire year or a fraction thereof. Consequently, the period that an individual was at risk for suicide was defined as the duration of life in 1985 following the diagnosis of AIDS. To calculate the period of risk, an individual with AIDS was assumed to have been diagnosed at midmonth. When death resulted, it was assumed to have occurred at midmonth. Individuals who were diagnosed and died in the same month were considered to be at risk for 0.5 months. Therefore, the period of risk was determined to be the number of months from the date of diagnosis as reported to the AIDS Surveillance Unit or Jan 1, 1985, whichever was later, to the date of death or Jan 1, 1986, whichever was earlier. The "months at risk" in 1985 were tabulated individually for males and females by quinary cohort, and then divided by 12 to yield age- and gender-specific person-years at risk for suicide in 1985. The rate was defined as the number of suicides in the cohort divided by the number of person-years at risk for that cohort. The rates were expressed per 100 000 person-years. The relative risk of suicide in an age- and gender-specific AIDS cohort was calculated as the ratio of the suicide rate of that cohort to that of the general population.

Table 3.—Demographics and Circumstances of AIDS-Related* Suicides

Case No./Age, y/ Gender/Race†	Risk Factor‡	Previous Suicide Attempts	Suicidal Warning§	Recency of Psychiatric Contact	Suicide Note	Method	Location
1/22/M/H	Unknown	Yes	Yes	Unknown	Yes	Firearms	Home
2/33/M/W	H-B	Unknown	Unknown	Unknown	No	Barbiturate ingestion	Home
3/33/M/B	H-B	Yes	Unknown	1 d	No	Fall from height	Home
4/34/M/W	H-B	Yes	Yes	4 d	No	Fall from height	Home
5/34/M/W	Unknown	Yes	Yes	4 d	No	Fall from height	Medical ward
6/36/M/W	Unknown	No	Yes	Unknown	Yes	Cyanide ingestion	Home
7/36/M/W	H-B	Unknown	Unknown	Unknown	No	Fall from height	Medical ward
8/40/M/W	H-B	No	No	Unknown	No	Fall from height	Home
9/41/M/H	H-B	Unknown	Yes	1 d	No	Fall from height	Medical ward
10/42/M/B	H-B	No	Unknown	Unknown	No	Hanging	Home
11/43/M/W	H-B	Unknown	Unknown	1 d	Yes	Fall from height	Home
12/56/M/H	Unknown	No	No	Unknown	No	Hanging	Home

*AIDS indicates acquired immunodeficiency syndrome.
†H indicates Hispanic.
‡H-B indicates homosexual-bisexual.
§Expressed suicidal intent to others before death.

RESULTS

Suicide Rates Among the General Population

The total number of suicides committed by residents of New York City from Jan 1, 1985, through Dec 31, 1985, was 668, of which 3% (19) were certified outside the geographic boundaries of the city. Table 1 summarizes the age-specific rates for male residents. Among men aged 20 to 59 years (New York City population, 1 860 868), the group most at risk for AIDS, the overall suicide rate was 18.75 deaths per 100 000 person-years of life. The suicide rate for females aged at least 10 years was 4.73 per 100 000 person-years. The combined rate for male and female New York City residents aged at least 10 years was 9.29 per 100 000 person-years.

Suicide Rates Among the AIDS Population

There were 3828 New York City residents who lived with a diagnosis of AIDS for some part of 1985. These included 3475 men who contributed a total of 1787.1 person-years of life with AIDS. The 353 females contributed 165.5 person-years of life with AIDS. There were 12 suicides among AIDS cases, all occurring in men aged 20 to 59 years. Table 1 summarizes the age-specific rates for males, as well as the number of person-years and total population of each five-year cohort. The rate of suicide for men aged 20 to 59 years diagnosed with AIDS was 680.56 deaths per 100 000 person-years of life with AIDS. This represents a relative risk 36.30 times (95% confidence limits, 20.45 to 64.42) that of men in this age group in the general population (Table 2). The rate for males and females older than 10 years diagnosed with AIDS was 614.50 deaths per 100 000 person-years of life with AIDS, which yields a relative risk 66.15 times (95% confidence limits, 37.38 to 117.06) that of the general population.

Demographics of AIDS-Related Suicides

Among AIDS patients of the 12 suicides, seven were white, three were Hispanic, and two were black (Table 3). The mean age (± SD) at suicide was 37.5 ± 8.1 years (median, 36 years). Seventy-five percent (nine) were homosexual or bisexual. Risk factors for AIDS could not be determined for the remaining cases; however, there was no history of blood transfusion or evidence of intravenous drug abuse, ie, needle tracks or a record of drug abuse. Eight resided in New York County (Manhattan), two in Queens County, and two in Kings County (Brooklyn). Ten of the 12 were unmarried; in one case marital status was unknown. Nine of the 12 were recently employed or students. Two were health professionals whose risk status was not known to be related to occupational exposure. In one case occupational status was unknown. All committed suicide within nine months of receiving the diagnosis of AIDS, most within six months of diagnosis. On autopsy none of the victims appeared to have been wasted, suggesting that all were at relatively early stages of the illness.

Circumstances of the AIDS-Related Suicides

The suicide methods chosen by the victims included fall from height (seven), hanging (two), gunshot wound to the head (one), and ingestion of barbiturates (one) or cyanide (one). Some acts of suicide could be characterized as markedly impulsive and sudden, whereas others were more carefully executed with premeditation. Three persons left suicide notes. Before committing suicide, one individual violently resisted intervention. Three suicides (25%) occurred in the medical units of general hospitals and all of these were accomplished by jumping from windows.

Results of toxicologic analysis were positive for cocaine and barbiturates in one case. Findings from toxicology screens were negative for ethyl alcohol; cocaine, morphine, opiates, and other basic drugs; and acidic drugs in eight cases. In three cases, autopsies were not conducted either due to religious objections raised by the family (two) or the medical examiner's review of the case (one). Consequently, toxicology testing was not conducted in these cases. There were two additional suicides (which were not confirmed AIDS cases) in which family interviews and suicide notes suggested that the recent death of a homosexual lover with AIDS was a precipitant for the suicide. In what appeared to be a suicide pact, an AIDS victim and his companion, not known to have AIDS, jointly committed suicide.

Psychiatric Status of the AIDS-Related Suicides

Detailed "psychological autopsies" of these AIDS-related suicides are beyond the scope and methods of this study. Nevertheless, certain important psychiatric data can be reported from information obtained from medical examiner records and medical examiner and police investigations involving family members, friends, and the treating physicians of the suicide victims (Table 3). Four persons had each made one previous suicide attempt; in two cases the attempt was made after the diagnosis of AIDS and within one month of the completed suicide. Four individuals had never attempted suicide previously. In four cases, a history of previous attempts was not known. Five persons expressed suicidal ideation to family, friends, physicians, or the police in the days before their suicide. Two persons gave no warning of their suicidal intentions, and whether suicidal ideation was expressed was unknown in five cases.

Two individuals had been treated in psychiatric hospitals for depression within one month before their suicide. In an additional four cases, the family reported the individuals were profoundly depressed over their medical condition. One individual reportedly suffered from chronic anxiety following the diagnosis of AIDS. Information about psychiatric diagnoses made before the diagnosis of AIDS is uncertain.

In five of the 12 cases, individuals had seen a psychiatrist within four days before suicide. Two of these individuals had been released from a psychiatric hospital four days earlier. Another two had seen psychiatric consultants on a medical service within the preceding 24 hours of suicide; one committed suicide at home and another committed suicide on the medical ward, despite the presence of constant one-on-one monitoring by nursing staff. In another case, an individual committed suicide at home 24 hours after seeing a psychiatrist in an emergency department.

COMMENT

The acquired immunodeficiency syndrome has exerted a significant impact on the premature mortality of young males in New York City in the 1980s. It is the leading cause of death among men aged 30 to 39 years in New York City.[16] To our knowledge, this is the first study to demonstrate a substantially increased risk for suicide among males with AIDS. Men aged 20 to 59 years with a diagnosis of AIDS are approximately 36 times as likely to commit suicide than men in the general population. The profile of the typical individual with AIDS who commits suicide is that of an unmarried, white, homosexual man aged 37 years, who has known the diagnosis for less than six months.

In this study the absence of suicide in women with AIDS is best explained by their overall small representation in the AIDS population. Additionally, the rate of suicide in females is less than that of males, in part, due to differences in risk factors.[17] If one considers a ratio of 3.5:1 for male suicides over those of females, a male rate of 671 per 100 000 person-years of life with AIDS and a concomitant female rate of 191 per 100 000 person-years of life with AIDS would require 524 female person-years of life with AIDS to yield one suicide among females diagnosed with AIDS. As described above, there were only 165.5 person-years contributed by females with AIDS.

The high proportion of AIDS-related suicides that occurred in hospitals is striking. These suicides are sudden and impulsive, raising the possibility that delirium may have precipitated them.

Two other suicides of persons without AIDS appeared to be related in part to the earlier death of the victim's lover due to AIDS. The propensity toward suicide in certain individuals during the bereavement phase may be compounded by the individual's fear of contracting the same terminal illness.

The high suicide rates observed in the AIDS population may result from an additive confluence of factors known to be associated with higher suicide rates in populations without AIDS. The acquired immunodeficiency syndrome has been associated with secondary depression and other psychiatric syndromes, eg, dementia, paranoia, psychoses, organic affective syndrome, and delirium, all of which are associated with higher suicide rates.[9-12,14]

The risk of suicide is reported to be higher in medically ill persons.[18] The relative risk of suicide is increased only modestly in certain diseases that do not predominantly affect the central nervous system.[18] For example, several studies have found an observed-to-expected suicide death ratio in persons with peptic ulcer disease of two to nine times that of the general population.[19-21] Both preexisting and illness-induced psychosocial stressors have been invoked to explain this increased risk. Many illnesses share common stressors, eg, reduced physical functioning, long-term dependency, hopelessness, or uncertainty about cure. Each illness may also have unique stresses that predominate, eg, dependence on dialysis machines or chronic cancer pain. Psychosocial stressors that may serve as precipitating factors in persons with AIDS include the social stigma of the illness, the withdrawal of family support, diminished or lost occupational functioning, long-term dependency, the loss of friends or lovers of the victim (often to AIDS), and the spector of an inexorable, terminal illness that may lead to pain, disfigurement, and emaciation. The relative importance of these individual stressors in contributing to suicide risk is unknown. In addition, illnesses affect different segments of the general population. Thus differences in these demographics and stressors may account for some of the variability in suicide rates associated with various medical illnesses, including AIDS.

Suicide rates associated with disorders of the central nervous system seem to be at least one order of magnitude greater than those associated with disorders not involving the nervous system. For example, suicide among temporal lobe epileptics is noted 25 times more frequently than expected.[22] Another study showed persons with multiple sclerosis had a suicide rate 14 times that expected.[23] The magnitude of the relative risk of suicide among persons with AIDS is comparable with or greater than that of Huntington's disease. These high suicide rates, which are comparable with those observed in major psychiatric disorders, suggest a possible role for a biological mechanism contributing to suicide in persons with these disorders. Both AIDS and Huntington's disease, for example, are strongly associated with psychiatric syndromes, including depression, psychosis, and dementia.[4,12-14] In recent years, studies have found links between violent suicidal behavior and altered neurotransmitter functioning.[24] Postmortem brain studies have shown that decreased serotonergic functioning is associated with violent suicide.[25] This raises the possibility that the human immunodeficiency virus (HIV) or other opportunistic infections of the central nervous system may exert either a direct affect on serotonergic pathways or affect other neurotransmitter systems implicated in depression. In addition, several drugs used to treat AIDS-related infections (including pentamidine isethionate, sulfamethoxazole and trimethoprim, and amphotericin B), although not specifically linked to serotonergic changes, have been associated with psychosis and delirium, conditions that increase suicide risk.[26-29]

Thus, the AIDS-related suicide rates, which are as high or higher than rates reported in other studies of central nervous system disorders, may be attributed to a powerful confluence of biologic factors, specific demographics and psychosocial stressors unique to this illness.

There are several reasons to suspect that the rates reported in this study underestimate the true AIDS-related suicide rate. First, there may have been suicide victims in whom the diagnosis of AIDS was not reported to the medical examiner, and in the absence of HIV testing would not be suspected (HIV testing is not routinely performed on medical examiner cases). Second, suicides may be "hidden" in other manner of death classifications. For example, deaths in which the cause is listed as "acute or chronic intravenous narcotism" may not be classified as suicide, but rather as "undetermined" for reasons previously noted in the "Methods" section. Thus, the absence of suicides among AIDS patients whose primary risk factor is intravenous drug abuse may be an artifact of case finding. For example, the Bronx area contributed 14% of New York City AIDS cases from 1979 through 1985, a majority of which were derived from intravenous drug abusers, yet no AIDS-related suicides were documented in this borough.[30] Third, many AIDS deaths are assumed to be due to the natural course of an illness with a high mortality rate. Some, in fact, may represent overdoses of prescribed medications or other drugs and may escape the scrutiny of a postmortem examination. It is also difficult to estimate the number of individuals with AIDS in whom refusal of treatment or reckless behaviors represent suicidal equivalents. Nineteen New York City residents committed suicide in jurisdictions other than New York City and their deaths were certified in those jurisdictions. These particular cases were not reviewed. Possibly some of these individuals had AIDS diagnosed before death and were not counted in this study.

The recency of AIDS as a disease phenomenon, the small numbers of persons with the disease before 1984, and the lag time in record keeping allow examination of suicide rates over a one-year period only. Thus, the stability of these rates or trends over time cannot be ascertained from these data. Although the age- and gender-specific relative risks reported in Table 2 range as high as 180 times that of the general population, the small number of cases prohibits making specific rate predictions within five-year age cohorts. Additionally, comparison of the AIDS-related suicide rate with suicide rates in more suitable control groups, ie, homosexuals or drug users without AIDS, is complicated by methodologic difficulties in identifying and studying these populations.

CONCLUSIONS

We believe this study has several implications for the treatment of patients with AIDS. In light of the high rate of suicide in patients with AIDS and the tendency for these suicides to occur early in the course of the illness, physicians should evaluate suicide risk in these patients carefully. Because of this risk for suicide, the presence of concomitant psychiatric syndromes, especially depression and delirium, should lead to early psychiatric intervention. Although the illness is terminal, efforts at suicide prevention are appropriate to allow patients to rationally evaluate alternatives to treatment, to integrate their lives in terms of financial and other planning, and to allow resolution of personal relationships with family and friends.

There are several important long-range public health implications as well. First, the incidence of AIDS is still increasing, rendering a larger portion of the general population at risk for AIDS-related suicide. Second, the high rate of suicide among persons with AIDS may portend elevated rates of suicide in populations at risk of contracting AIDS (eg, intravenous drug users, homosexuals, and individuals who are antibody positive), as well as those indirectly affected by persons diagnosed with AIDS (eg, family members of persons with AIDS). Third, recent advocacy of mass population HIV-antibody screening should be viewed cautiously, unless appropriate counseling can be offered concerning the ramifications of the illness and the significance of the test results.

Future research, perhaps involving the prospective follow-up of a large AIDS cohort, should be undertaken to examine the association of AIDS-related neurological and psychiatric syndromes with suicide risk, to futher elucidate the profile of the AIDS victim at greatest risk, to assess better the role of both organic (drug and viral) and psychosocial factors as precipitants, and to study suicide trends in this population over time. Likewise, the prospective follow-up of groups at high risk for AIDS, particularly those with a positive HIV titer, should be undertaken for similar reasons.

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Suicidal Ideation and HIV Testing

Samuel Perry, MD; Lawrence Jacobsberg, MD, PhD; Baruch Fishman, PhD

To examine the effect of human immunodeficiency virus antibody testing on suicidal ideation among physically asymptomatic subjects at perceived risk for infection, 244 men and 57 women completed the Beck Depression Inventory 2 weeks before and 1 week and 2 months after notification. All subjects received extensive pretest and posttest counseling. Among the 49 seropositive subjects, rates of suicidal ideation on item 9 of the Beck Depression Inventory were 28.6% at entry and 27.1% and 16.3% at the two follow-up assessments; none reported increased suicidal ideation at 2 months. Among the 252 seronegative subjects, suicidal ideation decreased from 30.6% at entry to 17.1% and 15.9% at 1 week and 2 months after notification, respectively. Suicidal ideation correlated with modified Beck Depression Inventory scores ($r = .50$ to .55). Among the 4.7% of seropositives and seronegatives with suicidal wishes or intent at any assessment, average modified Beck Depression Inventory scores (mean, 17.1) suggested a clinical depression.

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CONCERNS have been raised about the risk of suicide in individuals who have been informed that they are infected by the human immunodeficiency virus (HIV).[1] Support for these concerns comes from clinical impression,[2] case reports,[3-5] and studies of suicide in patients with the acquired immunodeficiency syndrome (AIDS).[6,7] Reviewing 1985 records of the medical examiner in New York, NY, Marzuk et al[6] calculated that the suicide rate of men with AIDS who were 20 to 59 years old was 36 times the rate of men without AIDS. Kizer et al[7] examined 1986 California death certificates and found that the relative suicide rate of men with AIDS aged 20 to 39 years was 21 times the rate of men without AIDS.

Although the above studies regarded patients with AIDS, their findings may partially explain the wariness among physicians to conduct HIV testing.[8] To examine whether this wariness is warranted, we assessed self-reported suicidal ideation among a physically asymptomatic at-risk cohort 2 weeks before and again at 1 week and 2 months after HIV serological notification. Because studies of patients with medical illnesses have found that suicidal ideation is rare in the absence of depression,[9-11] we also examined the relationship between suicidal ideation and other self-reported depressive symptoms.

METHODS

Subjects were recruited by newspaper advertisements, public service announcements, and descriptions of the study sent to medical clinics and drug rehabilitation programs throughout New York City. Free confidential testing with counseling in a private office was offered to physically asymptomatic adults whose serological status was unknown and whose HIV risk behaviors included intravenous drug use; homosexual intercourse; and heterosexual intercourse without condoms with prostitutes, multiple partners, and known or suspected intravenous drug users or bisexuals.

At the first appointment, subjects completed self-report measures,[12] including the Beck Depression Inventory (BDI).[13] A psychiatric nurse then provided pretest counseling,[14] a 1-hour session tailored to the knowledge and needs of the individual but always encompassing the sensitivity and prognostic meaning of the test; medical history; assessment of risk factors, vulnerabilities, coping capacities, and supportive resources; and a mutually negotiated decision about whether HIV antibody testing was advisable at the present time. After informed written consent was obtained, blood was drawn for immunoassay with Western blot confirmation. On return 2 weeks later, subjects were notified of test results and received posttest counseling,[14] a 1-hour session again tailored to the individual but always including an empathic response to initial reactions, education about how HIV is and is not transmitted, detailed explanation of preventive measures, and advice about informing others about test results. The BDI was completed 1 week and 2 months after notification.

On item 9 of the BDI, subjects endorsed 0 ("I don't have any thoughts of killing myself"), 1 ("I have thoughts of killing myself, but I would not carry them out"), 2 ("I would like to kill myself"), or 3 ("I would kill myself if I had the chance"). As with all BDI items, subjects are asked to rate the presence of this ideation during the past week. For the purposes of this study, "suicidal ideation" was defined as a score of 1 to 3. In addition, to estimate the potential severity of suicidal ideation, "suicidal

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Suicidal Ideation Before and After HIV Serological Testing in 301 Self-selected Physically Asymptomatic Subjects*

	Suicidal Ideation														
	2 wk Before Testing					1 wk After Notification					2 mo After Notification				
Subjects	Total No.	None, No. (%)	Thoughts, No. (%)	Wishes, No. (%)	Intent, No. (%)	Total No.	None, No. (%)	Thoughts, No. (%)	Wishes, No. (%)	Intent, No. (%)	Total No.	None, No. (%)	Thoughts, No. (%)	Wishes, No. (%)	Intent, No. (%)
All	**301**	**210** (69.8)	**81** (26.9)	**8** (2.7)	**2** (0.7)	**293**	**238** (81.2)	**50** (17.1)	**5** (1.7)	**0**	**301**	**253** (84.1)	**43** (14.3)	**4** (1.3)	**1** (0.3)
HIV –	**252**	175 (69.4)	69 (27.4)	7 (2.8)	1 (0.4)	**245**	203 (82.9)	38 (15.5)	4 (1.6)	0	**252**	212 (84.1)	35 (13.9)	4 (1.6)	1 (0.4)
HIV +	**49**	35 (71.4)	12 (24.5)	1 (2.0)	1 (2.0)	**48**	35 (72.9)	12 (25.0)	1 (2.1)	0	**49**	41 (83.7)	8 (16.3)	0 (0.0)	0 (0.0)

*HIV indicates human immunodeficiency virus.

thought" was defined as a score of 1, "suicidal wish" as a score of 2, and "suicidal intent" as a score of 3.

Although this report focuses on the immediate and intermediate effects of HIV serological notification on suicidal ideation, part of our ongoing study tests the effectiveness of three postnotification psychotherapeutic interventions in reducing chronic distress assessed 6 and 12 months after HIV testing.[12] After posttest counseling, subjects were randomly assigned to "standard practice," ie, only the pretest and posttest counseling described above; to six weekly sessions of stress-prevention training, which began the week after notification and included teaching methods of relaxation and reframing dysfunctional thoughts; or to three weekly sessions of a similar stress-prevention training program imparted by interactive video. To examine for effect of these three interventions on suicidal ideation, scores on item 9 of the BDI were submitted to repeated-measures multivariate analysis of variance with three factors: serology (seropositive vs seronegative), intervention (standard practice vs stress-prevention training vs interactive video), and time (entry vs 1 week after notification vs 2-month follow-up).

After preliminary exploration with repeated-measures analysis of variance, post hoc analyses were conducted where appropriate in which rates of item 9 scores were compared using the Mann-Whitney *U* Test for independent samples, the Wilcoxon's Rank Sum Test for repeated measures, and the McNemar's Test for paired dichotomous samples. To determine if suicidal ideation was associated with depressed feelings, estimates of depression were obtained by calculating modified BDI scores (ie, total BDI score minus the score on item 9), then two-tailed *t* tests and Pearson's correlation coefficient were used to examine the relationship between item 9 and modified BDI scores. Because many more subjects were seronegative than seropositive, separate variance estimates of the two serological groups were used in the *t* tests.

RESULTS

The initial sample of this ongoing study consisted of 244 men and 57 women with a mean age ($\pm$SD) of 32.6 ± 8.9 years (range, 18 to 66 years); 221 were white, 38 black, 29 Hispanic, 5 Asian, and 8 other. The median income was in the range of $15 000 to $30 000 (13 had no income, and 22 earned >$50 000 per year). Regarding highest educational level, 162 subjects had a college degree, 100 some college credits, and 23 a high-school diploma, and 16 had not completed high school.

Of the 301 subjects, a history of intravenous drug use was present in 36, of heterosexual risk behaviors in 75, and of homosexual intercourse in 199 (22 subjects reported multiple risk behaviors and 13 did not identify a risk behavior). Of the 49 seropositive subjects, 10 had a history of intravenous drug use with or without other risk behaviors and 38 reported homosexual intercourse as their only risk behavior; heterosexual intercourse was the sole risk behavior in only 1 seropositive subject (the female partner of a seropositive man).

An additional 53 subjects were entered but dropped out of the study before the 2-month assessment and were therefore excluded from analysis. Their entry values on multiple measures[12] did not differ significantly from those of the subjects who were followed up. Of these dropouts, 6 were seropositive; follow-up telephone contact brought 3 subjects back into the study after the 2-month assessment, at which time none reported suicidal ideation. Of the remaining 3 seropositive subjects, telephone interviews indicated that none had made a suicide attempt and that their stated reasons for discontinuing participation were not related to the distress of notification (ie, a move out of state to home, the inconvenience of missing work, and the rapid development of HIV-related blood dyscrasia).[12]

The multivariate analysis of variance indicated that the three postnotification interventions (standard practice, stress-prevention training, interactive video) did not have an effect on changes in scores on item 9 of the BDI either alone or in interaction with serology; however, there was a significant main multivariate effect on time ($\lambda = .949$, $P < .001$) and a significant serology-by-time interaction ($\lambda = .976$, $P < .05$).

The Table indicates scores on item 9 of the BDI 2 weeks before (mean, 16.6 days) and at 1 week (mean, 9.7 days) and 2 months (mean, 8.8 weeks) after notification. Among all subjects, rates of suicidal ideation fell from 30.2% at entry to 18.8% at 1 week (McNemar $\chi^2 = 17.8$, $P < .001$) and 15.9% at 2 months (McNemar $\chi^2 = 28.0$, $P < .001$). Between the two serology groups, entry rates of suicidal thoughts, wishes, and intent were nearly identical. At 1 week after notification, rates of suicidal thoughts were 15.5% among seronegative subjects and 25% among seropositive subjects, and rates of suicidal wishes were 1.6% and 2.1%, respectively. These distributions of scores did not differ significantly between the two serology groups (Mann-Whitney $U = 5300$, $P = .11$). About 2 months later, rates of suicidal thoughts, wishes, and intents between seronegative and seropositive subjects were again not significantly different (13.9% vs 16.3%, 1.6% vs 0%, and 0.4% vs 0%, respectively).

Among seronegative subjects 1 week after notification, rates of suicidal thoughts, wishes, and intents decreased significantly (27.4% to 15.5%, 2.8% to 1.6%, and 0.4% to 0%, respectively; Wilcoxon $z = -4.18$, $P < .001$) and remained significantly decreased at the 2-month follow-up (27.4% to 13.9%, 2.8% to 1.6%, and 0.4% to 0.4%, respectively; Wilcoxon $z = 3.99$, $P < .001$). Examination of change in scores on item 9 of the BDI among seronegative subjects revealed that, compared with entry values, at 2 months after notification 49 had decreased and 3 had increased suicidal ideation.

Among seropositive subjects, the number with suicidal thoughts did not change 1 week after notification (N = 12 [25.0%]) and decreased about 2 months later (N = 8 [16.3%]). The rate of suicidal wishes remained low among seroposive subjects 1 week (2%) and 2 months (0%) after notification. Overall, the distribution of responses among seropositive subjects did not change significantly between entry and 1 week after notification (Wilcoxon $z = -.49$, $P = .62$) but did change significantly between entry and about 2 months after notification (Wilcoxon $z = -2.2$, $P = .03$). Examination of change in scores on item 9 of the BDI within seropositive subjects revealed that, compared with entry, 1 week after notification five seropositive subjects had increased suicidal ideation and six had decreased suicidal ideation and that none reported increased suicidal ideation after 2 months. The only subject to report suicidal intent after notification was a depressed seronegative homosexual man with a modified BDI score of 37 at that time.

At entry the 91 subjects with suicidal ideation had a modified BDI score (14.9 ± 8.0) that was significantly higher than the modified BDI score (6.6 ± 5.9) of the 210 subjects without suicidal ideation ($t[133.5] = -8.94$, $P < .001$). The correlation between the presence of suicidal ideation and modified BDI scores was also significant ($r = .50$, $P < .001$). After notification, this relationship remained highly significant both at 1 week (16.4 ± 8.8 vs 6.1 ± 5.4; $t[63.8] = -8.28$, $r = .54$, $P < .001$) and at 2 months (15.5 ± 9.5 vs 4.6 ± 5.2; $t[52.5] = -7.77$, $r = .55$, $P < .001$). In addition, the average modified BDI score over the three assessments of the 14 subjects (4.7%) with suicidal wishes or intent was 17.1 ± 8.5 (range, 2.3 to 31.3) compared with 11.6 ± 7.1 (range, 0.3 to 31.7) among the 90 subjects (29.9%) who at any time reported suicidal thoughts but never suicidal wishes or intent ($t[16] = 2.32$, $df = 16.0$, $P < .05$).

COMMENT

Our finding that, on average, suicidal ideation did not increase after HIV testing is somewhat reassuring. During the week after notification, rates of self-reported suicidal ideation decreased significantly among the seronegative subjects and did not significantly increase among the seropositive subjects. About 2 months later, suicidal ideation had significantly decreased even among the seropositive sample.

Less reassuring is the finding that even in the context of confidential HIV testing with extensive pretest and posttest counseling of self-selected volunteers, suicidal ideation persisted after notification in over 15% of both the seropositive *and* seronegative groups. Most of these subjects endorsed only suicidal thoughts and not wishes or intent, and there was wide variability in their modified BDI scores; nevertheless, the fact that their mean modified BDI scores were significantly higher than those of subjects without suicidal thoughts and were in a range associated with moderate depression[13] suggests that a subgroup of at-risk subjects is experiencing notable emotional distress both before and after HIV testing.

Potentially most worrisome is the even smaller subpopulation of seropositive and seronegative subjects who reported suicidal wishes or intent both before (3.4%) and after (1.6%) notification. Their average modified BDI score (mean, 17.1) was significantly higher than that of subjects with only suicidal thoughts and in a range associated with more severe depression.[13] Since as many as 15% of patients with affective disorders are known to commit suicide and estimates suggest that 10 to 20 times as many make suicide attempts,[15,16] physicians must be alert to the possibility that a small but clinically meaningful subpopulation seeking the HIV antibody tests may require psychiatric treatment. An additional reminder comes from Marzuk et al,[6] who found in their postmortem review that most of the patients with AIDS who committed suicide showed evidence of a concomitant psychiatric disorder.

Before generalizing our findings, one must consider the focus, context, population, and methods of this study. We focused on the immediate and intermediate effects of HIV antibody testing, not on the longer-term effects of living with an incurable and stigmatizing infection or on the development of physical symptoms, both of which have been associated with increased psychological morbidity.[2,17,18] Our data, therefore, do not contradict the reports of increased suicide rates in patients with AIDS.[6,7]

Further, we were interested in assessing the impact of notification in a situation comparable with a physician's office. While not provided false reassurance, all our subjects were informed during confidential pretest and posttest counseling[14] about the prolonged average latency of HIV infection before the development of physical symptoms, about how the annual mortality rate of patients with AIDS has decreased markedly in just the past few years, and about the efficacy of current maintenance antiviral medications and the promise of future drugs.[19] Subjects left the counseling sessions with the explicit message that seropositivity was not synonymous with AIDS and should not be viewed as an imminent "death sentence." Implicitly, the message was that "rational suicide" should be viewed, at the very least, as premature. Because of this provision of extensive counseling with the inherent support of a physician-patient relationship, our findings may not apply to HIV antibody testing conducted in other contexts, such as mass screening of military personnel and blood donors,[20] of serological notification of stored serum samples,[21,22] and possibly of individuals tested at alternative ("anonymous") sites. Furthermore, although the additional psychoeducational interventions (into which two thirds of the subjects were randomly assigned after notification to test their effectiveness in reducing *chronic* distress) did not have an immediate impact on suicidal ideation, these interventions doubtlessly provided more support than most individuals receive when seeking the HIV antibody tests. The low base rates of suicidal ideation may explain in part the statistically nonsignificant effect of the postnotification interventions.

Every sample of individuals at perceived risk for HIV infection is subject to its own selection biases. Although our cohort was diverse in terms of age, sex, race, education, annual income, and HIV risk behaviors, one could contend that our methods of recruitment and the burdens of the study attracted an emotionally healthier population. However, we have found[23] that, compared with community samples, our subjects have markedly higher rates of current and lifetime depressive disorders and of alcohol and nonintravenous substance dependence, all of which are associated with increased suicidal risk.[15,24-26] The high rate of suicidal ideation at entry (30.2%) also would suggest that we were not studying a sample with low vulnerability, but we would encourage others to conduct similar studies of different samples to determine the generalizability of our results, especially among populations with relatively more intravenous drug use and with relatively less education, affluence, and access to mental health or other supportive services.

Finally, by comparing scores on item 9 of the BDI before and after notification, we evaluated changes in suicidal ideation. We did not determine suicidal risks, for which more extensive instruments have been developed that additionally assess hopelessness, substance use, past suicide attempts, current suicidal plans, etc.[16,27-29] Most patients with suicidal thoughts do not commit suicide,[25] and an elevated BDI score is not in itself diagnostic of clinical depression.[30] However, since suicidal ideation is an important component of suicidal risk[29] and since patients frequently prefer to give information via self-ratings rather than during a personal interview,[31] our data at least provide an estimate of psychiatric vulnerability and another step toward understanding this at-risk population.

Although rates of suicidal ideation did not increase among our self-selected cohort after HIV notification, the above considerations offset any premature conclusions that the HIV testing process can be approached "routinely." Rather, our preliminary findings indicate that pretest and posttest counseling can provide an opportunity to identify a subpopulation at risk for psychiatric morbidity.

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"THE WORRIED WELL" (those people who have not taken the HIV antibody test and who are asymptomatic for infection, but are worried about getting AIDS)

- Will I get it? Am I infected?
- Should I take the test and then worry myself more if it's positive?
- How safe is "safe sex"?
- Should I be celibate?
- Will there ever be a cure, vaccine, etc.?
- What do I do to stay healthy?
- Will others ostracize me if they know I'm at risk?

SEROPOSITIVE

- Should I tell my sexual partner(s)?
- Will anyone want to have sex with me if I do tell?
- Will I develop ARC or AIDS
- When will I start getting sick?
- Should I change my lifestyle, and if I do, will it keep me from getting sick?
- Can I take any medication that will help?
- Why me? From whom did I get it? When?
- Should I tell my family and friends?
- Will others be fearful to be near me?
- Will I lose my job, apartment, etc., if someone knows?
- Will I be one of the lucky ones who doesn't get sick?

ARC

- When will I develop AIDS?
- How do I manage with all the symptoms?
- What benefits, assistance, can I get?
- How do I go about getting help?
- How will I support myself?
- How will I pay for treatment?
- Whom can I tell?
- What about my sex life? Do I need to be celibate?
- Is my lover infected?
- Where did I get it from? Who?
- Should I tell my family? Will they reject me?

AIDS

- How soon will I die?
- Should I kill myself before it gets too bad?
- Can I stand the pain and suffering?
- Will my friends/significant others stand by me?
- How do I get my affairs in order?
- How will I support myself?
- Who will take care of me?
- Will a cure be found before it's too late?
- Will experimental drugs prolong my life?

SOURCE: G. Gee, "Individual Psychosocial Responses to HIV Infection," in AIDS: Concepts for Nursing Practice, edited by G. Gee and T. Moran. Williams & Wilkins Publishers, Baltimore, MD. 1988.

AREAS OF LOSS FACING PEOPLE WITH HIV INFECTION

LOSS OF FUNCTION:

- Fatigue, decreased energy levels
- Loss of motor control; especially upper and lower extremities
- Loss of cognitive function; memory loss, confusion, apathy, disorientation
- Loss of self
- care capabilities
- Loss of sensory reception

LOSS OF APPEARANCE:

- Severe weight loss, cachexia
- Kaposi's Sarcoma lesions; edema secondary to lymphnode blockage

LOSS OF SOCIAL INTERACTION:

- Physical disability and chronic illness limiting social activities
- Loss of intimate relationships related to fear of contagion
- Loss of friendships related to fear of contagion and death
- Family estrangement related to stigma of diagnosis, fear of contagion
- Loss of friends by death from AIDS

LOSS OF USUAL SEXUAL FUNCTION:

- Change in sexual activities to avoid transmission
- Choosing celibacy
- Decreased ability to engage in sex, secondary to chronic illness, fatigue
- Decreased libido, secondary to illness, depression, medication

LOSS OF CONTROL OVER ONE'S LIFE (including status, lifestyle, roles)

- Loss of family and community standing related to diagnosis
- Loss of employment, income, medical benefits
- Loss of identity as worker, family head, lover, self
- supporting person
- Loss of one's own life

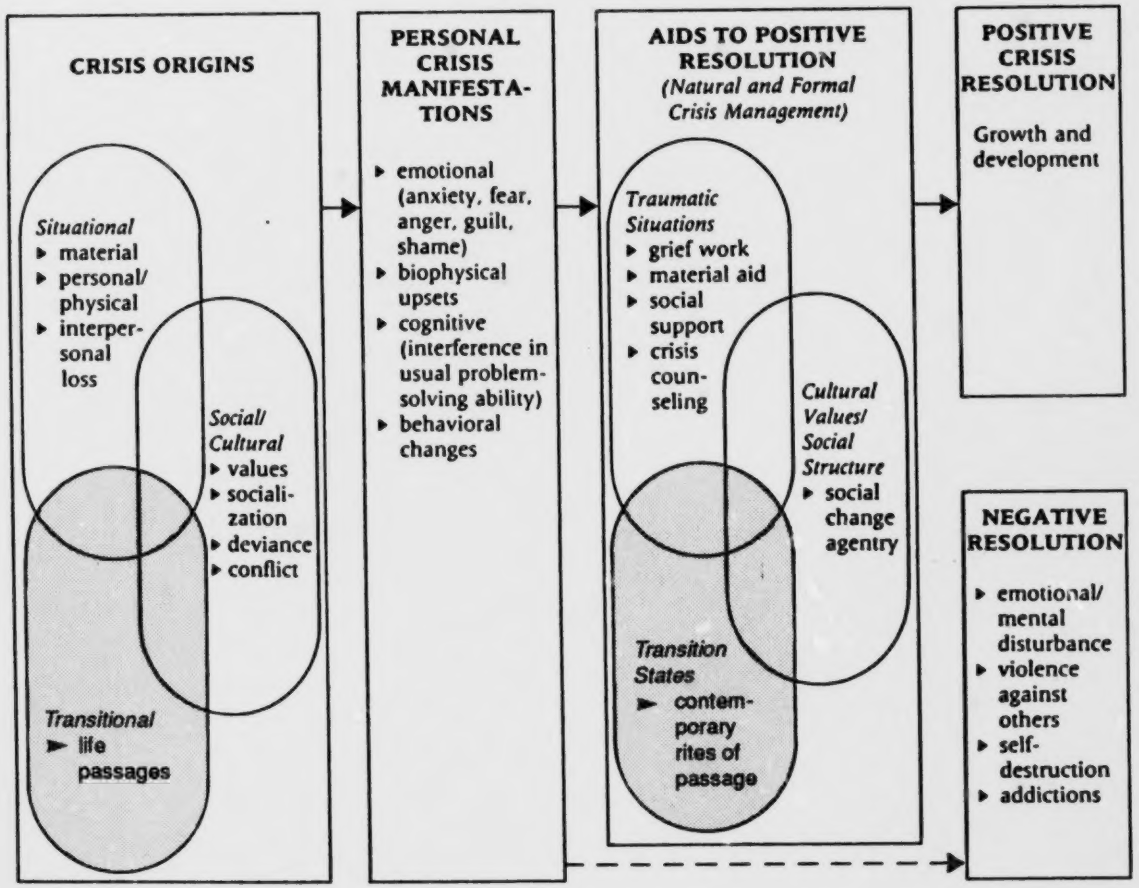
SOURCE: G. Gee, "Individual Psychosocial Responses to HIV Infection," in
AIDS: Concepts in Nursing Practice, edited by G. Gee and T. Moran.
Williams & Wilkins Publishers, Baltimore, MD. 1988.

CRISIS INTERVENTION TECHNIQUES

- * Relieve Isolation
- * Remove Lethal Weapons
- * Encourage Alternate Expression of Anger
- * Avoid Final Decision of Suicide During Crisis
- * Re-establish Social Ties
- * Relieve Extreme Anxiety and Sleep Loss

CRISIS PARADIGM

Crisis origins, manifestations, and outcomes, and the respective functions of crisis management in interactional relationship applied to a person with AIDS or testing HIV positive. The solid line from "origins" to positive resolution illustrates the *opportunity* for positive outcomes of the AIDS crisis; the broken line depicts the potential *danger* of the AIDS crisis in the absence of appropriate aids to individuals and responses by society.


CRISIS ORIGINS
Situational
▸ material
▸ personal/ physical
▸ interpersonal loss
Social/ Cultural
▸ values
▸ socialization
▸ deviance
▸ conflict
Transitional
▸ life passages
PERSONAL CRISIS MANIFESTATIONS
▸ emotional (anxiety, fear, anger, guilt, shame)
▸ biophysical upsets
▸ cognitive (interference in usual problem-solving ability)
▸ behavioral changes
AIDS TO POSITIVE RESOLUTION
(Natural and Formal Crisis Management)
Traumatic Situations
▸ grief work
▸ material aid
▸ social support
▸ crisis counseling
Cultural Values/ Social Structure
▸ social change agentry
Transition States
▸ contemporary rites of passage
POSITIVE CRISIS RESOLUTION
Growth and development
NEGATIVE RESOLUTION
▸ emotional/ mental disturbance
▸ violence against others
▸ self-destruction
▸ addictions

Source: People In Crisis: Understanding and Helping. Lee Ann Hoff.
Addison-Wesley Publishing Company, Inc. Third Edition, 1989.

Countertransference Issues in Working with Persons with AIDS

Joan Dunkel
Shellie Hatfield

In the current AIDS epidemic, social workers must interact with numerous systems—persons diagnosed with AIDS and their friends and families and human services agencies. Subsequently, workers must deal with their responses to such interaction, including countertransference. The authors highlight eight countertransference issues that workers typically confront and present strategies for dealing with these issues.

IN JUNE 1981, the Centers for Disease Control first reported unusual cases of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma in homosexual and bisexual men.[1] These cases, associated with profound immunosuppression, were eventually identified as a specific disease entity and named acquired immune deficiency syndrome (AIDS). The underlying cause of the disorder has not been determined, nor is it known which risk factors are causative and which are contributory. Persons with AIDS have demonstrated an inability to fight disease because of gross impairment to the immune system. Scientists suspect that a transmissible agent, human T-cell lymphotropic virus (HTLV-III), is responsible for the disease. Data accumulated suggest that the viral infection is spread through sexual contact and blood contact and by vertical transmission from infected mothers in utero or during delivery. Currently, no evidence indicates that AIDS is spread by any other method.[2]

Although gay men between the ages of 25 and 44 account for more than 72 percent of the reported cases, AIDS is documented in gay men under the age of 20 and over the age of 50. AIDS also is reported in other groups identified as being at high risk for the disease: heterosexual intravenous drug users of both sexes, hemophiliacs who receive factor VIII concentrate, and children of parents in one of the high-risk groups.[3] AIDS was first seen in San Francisco, New York, and Los Angeles and has spread throughout the country. As of November 1985, there were 14,519 documented cases of AIDS in the United States, and 7,450 known deaths. No person has been known to recover fully from this disease.[4]

AIDS presents both a medical and a human challenge for health care providers. The role of social work is a particularly sensitive one because the social worker interacts with numerous systems, including (1) individuals with AIDS, as well as their families, friends, and lovers; (2) the "worried well" in the gay community, that is, persons without a diagnosis of AIDS but whose lifestyle has been similar to those with AIDS or persons who consider themselves to be in one of the high-risk categories; (3) health care providers who may or may not be homosexual; and (4) the larger legislative/political systems as they have an impact on health care. The social worker is responsible for providing direct clinical services to the client system as well as consultation, education, and support to other members of the health care team. However, the difficulty in sorting out and understanding personal and professional responses to issues raised by a population that is doubly stigmatized by being homosexual and by having a sexually transmitted disease may discourage some providers from either working effectively or working at all with persons with AIDS.

This article examines, within the conceptual framework of countertransference, issues, feelings, biases, and fears that have been identified by the authors in working with gay males with AIDS and with health care providers. It also suggests strategies for coping with countertransference on individual and group levels.

Countertransference, as an unconscious process involving the therapist's unresolved conflicts, both positive and negative, was first identified by Freud in 1910 and later expanded to include a conscious response to a "seductive" patient.[5] Freud saw the therapist's feelings as an impediment to the treatment process, and until recently, this concept remained with only minimal exploration and development. In 1950, Heimann used the term "countertransference" to include all feelings experienced by the therapist toward the patient that, rather than something to avoid, were often the key to the patient's unconscious.[6] Beitman, along with others, described countertransference as a conscious, preconscious, and unconscious process and suggested that when identified, countertransference provides useful data for diagnosis and intervention.[7] But the problems of countertransference responses continue to be addressed, and Langs pointed out that these responses may be prompted by some event in the therapist's life and may exist to gratify the therapist's needs rather than the patient's therapeutic endeavors. Such gratification alleviates anxiety and guilt or involves fantasies of rescue.[8]

A review of the recent literature reveals increasing attention to countertransference issues with various populations, including people who are terminally ill, who are mentally ill, who belong to the counter-

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culture, and who are homosexual.[9] The relationship between empathy and countertransference was examined by Peabody and Gelso, whose findings suggested a positive correlation between the therapist's ability to be empathic and openness to countertransference feelings.[10] Florence Joseph described eloquently her own countertransference with a dying patient:

> I have more than a suspicion that in my treatment of Alice, despite the sacrifice involved, I was deriving a great deal of gratification. In my own family constellation, as the youngest child in a large group, I grew up feeling that I lacked a responsible role in matters of importance. I had often fantasized being chosen by my parents, my teachers and my friends as a leader whom others followed with trust and confidence. During Alice's last months, in her time of need, I was, I am certain, the most important person in her life. *The deep roots of one's neurotic tendencies are never completely eradicated even by the most thorough analysis. In moments of crisis they are apt to show their presence.* [Italics added.][11]

For the purposes of this article, countertransference refers to those conscious, preconscious, and unconscious responses and feelings of the therapist that can be both a problem and a valuable therapeutic and diagnostic tool.

ISSUES

The authors have identified eight countertransference issues reported by health care providers, including social workers, who work with persons with AIDS: (1) fear of the unknown; (2) fear of contagion; (3) fear of dying and of death; (4) denial of helplessness; (5) fear of homosexuality (homophobia); (6) overidentification; (7) anger; and (8) need for professional omnipotence.

Fear of the Unknown

There is much about AIDS that remains unknown. The cause of the disease, its means of transmission, methods to alter its course, and even the population at risk of contracting it may be an unknown to many social workers. The "population"—as exemplified by one person—can easily become the "other," and the empathic process that is central to the helping relationship may not easily occur or may not occur at all. Detachment, which can give the appearance of objectivity, replaces the process of empathy and objectivity. The client who remains an unknown runs a greater risk of being the recipient of both conscious and unconscious countertransference. It becomes particularly important to get information regarding AIDS and homosexuality and to personalize the person who has AIDS.

Fear of Contagion

The fear that AIDS can somehow be transmitted through the air or by contact with the skin has been a common misconception since the syndrome was identified as infectious. The AIDS task force at the University of California Medical Center in San Francisco developed recommendations for precautionary measures, which focus on prevention of infection as well as on humanistic concerns.[12] These measures primarily call for careful hand washing and for the wearing of gloves whenever in direct contact with body fluids. Nevertheless, many health care providers remain fearful. They question whether enough is known about AIDS to say that contagion by proximity is impossible. The precautions currently operating in San Francisco represent a reasonable, well-thought-out plan for the control of AIDS and its associated infections. However, from time to time, the fear of contagion may accelerate into a panic reaction, which would make it difficult for either medical or psychosocial needs to be addressed appropriately.

The fear expressed by health care providers of being contaminated and of passing on the contamination to family and friends reflects how little is known about AIDS. In this respect, the fear of AIDS may have similarities to the fears aroused by earlier epidemics.[13]

Fear of Dying and of Death

Separate from the fear of the unknown and the fear of contagion, but linked to both, is the fear of death and of the person who is dying—as if death, too, might be transmissible. This is not an uncommon dynamic, particularly among health care providers who place such a high priority on "beating" death.[14] Working with a person who is dying challenges unresolved feelings regarding one's own mortality. Individual death is considered in relation to oneself, or one deals with the conflict surrounding mortality by denying the existence of death by denying the *personhood* of the person who is dying. This conflict can be exacerbated by the untimely death of a young person.

Denial of Helplessness

The person with AIDS activates a sense of helplessness in the health care provider that is difficult to acknowledge. On the one hand, the provider's denial of helplessness can be adaptive: it maintains hope for the individual with AIDS and for the effort to eliminate the syndrome. On the other hand, however, by denying helplessness, the worker may unconsciously try to gain control of the situation through a magical belief in his or her own omnipotence. When this magical control fails, the worker may experience personal failure and guilt.[15] This experience may result in the worker providing less than optimal care to persons with AIDS or even refusing to work with this population.

Fear of Homosexuality

Although only ego-dystonic homosexuality is included in the *Diagnostic and Statistical Manual of Mental Disorders*,[16] it would be incorrect to suggest that homosexuality is now accepted as "normal" by all of the lay and professional community. It would also be naive to assume that social workers, despite their values of respecting the uniqueness of each individual, are immune to homophobia. Pillard, referring to minority group stigmatization, noted the "ghettoization" of homosexuals:

> Psychological ghettoization is accomplished by avoiding contact with minority members so that feelings of empathy, of shared humanity, are not formed and so that pejorative characteristics can be more easily ascribed. Information about the minority, which is often misinformation, is derived from "experts" who have little genuine relationship with the minority members themselves.[17]

The psychological ghettoization of homosexuals results in the following: (1) developmental delay for some homosexuals who did not have the opportunity to master intimacy in their teens and early twenties; (2) internalization of the dominant group's perception of gays so that homophobia is experienced by both gays and straights (heterosexuals); (3) fear of homophobia by those who view themselves as liberal or liberated; and (4) unresolved homosexual feelings in straight health care providers, which may be reactivated by gay clients. It is appropriate that social work interventions with health care providers address these issues, but the effective use of interpersonal skills requires careful attention to both self-education and self-monitoring.[18]

Overidentification

Inherent in the empathic process is the ability to feel with the client and, therefore, identification is a necessary part of the therapeutic relationship. Overidentification occurs when the ability to return to an objective stance is lost. This can result in the worker's investing unrealistic amounts of time and energy in the client, fusing personal needs and professional responsibilities, and, in extreme cases, generating symptom formation. The homosexual health care provider may identify most sensitively with the person with AIDS and, thus, may be particularly vulnerable to overidentification.

Anger

The worker may experience anger because of feelings of helplessness, fear, and guilt, which result in "blaming the victim." Anger can be an unconscious attempt to punish, leading to irrational, explosive, and unpredictable behavior on the part of the worker. Anger that serves to distance the worker from the client is a form of self-preservation and serves to protect the worker from experiencing the pain of loss and death. The natural resistance to death can be experienced as anger toward the person who has AIDS and can consciously or unconsciously provoke the client to decrease the number of contacts with the worker. It is then easy for the worker to rationalize the decreased contacts as being client initiated. Such countertransference blocks empathy and prevents the therapist from being emotionally available during the stages of client need. The worker can successfully avoid grief and, therefore, "save" himself or herself for clients who have a chance of survival. This kind of reaction must be addressed, because one of the critical requirements for working with the person with AIDS is the worker's availability, reliability, empathy, and ability to respond emotionally to the client, particularly during times of regression.

Last, anger is misdirected that strikes out against the political and moralistic tones of the AIDS epidemic. The worker can use an individual with AIDS as a tool to gratify the sense of wanting to get back at society for discriminating against minority groups. As the worker pursues this larger cause and begins viewing the client unconsciously as a means to a political end, he or she loses objectivity and ceases to see the individual as unique. This kind of countertransference anger may be more prominent for the homosexual worker or the minority worker whose own sense of oppression is activated in the course of working with the person with AIDS.

Need for Professional Omnipotence

When the professional standards considered intrinsic to social work, such as human dignity and self-determination,[19] are expressed as the basic right of the consumer, the power base in the relationship shifts and the perceived authority inherent in the professional role is jeopardized. The person with AIDS who, for example, asks not to be labeled "patient" and refuses to assume the "patient's role," can threaten the worker's expertise and power by not recognizing or appreciating the worker's role. A social worker, usually confident of his or her skills in client advocacy, may become angry or resentful if the client assumes advocacy as a right.[20]

Although social work training and values provide a unique preparation for working with persons with AIDS, adhering to these values can present a challenge to social workers' personal belief system and professional role identity that may not be acknowledged. As described by Mendes, the personal and professional challenge is not only to maintain objective empathy at the same time rejecting the values of others, but also to remain responsive to clients who actively reject workers' values.[21] Rather than being aware of feelings and admitting to negative ones, professionals may find it easier to deny them, or to find reasons not to work with people who activate them.

CASE HISTORY

Mr. M, a married, 30-year-old white male diagnosed with Kaposi's sarcoma and *Pneumocystis carinii* pneumonia, was hospitalized for respiratory distress and failure to thrive. Mr. M's primary nurses were concerned about his apparent denial of the severity of his condition and his denial of having AIDS. They believed that he would benefit psychologically by "making peace with himself and his situation" and referred him to Mrs. S, the hospital unit's social worker, for help with his denial.

Mrs. S learned that Mr. M's parents and two siblings lived in the area. She also learned that Mr. M had had two secret affairs with homosexual men since his marriage. One of these men had died recently from AIDS. Mr. M also informed her that his family, wife, and physician knew nothing about the nature of his sexual identity. He said he was very close to "coming out" to his wife and family when he became ill.

During the first two days of Mr. M's hospitalization, Mrs. S gathered pertinent information and provided supportive counseling, but grew increasingly anxious. She reported that Mr. M behaved "seductively" with her when staff were present and wanted her to hold his hand. She interpreted his behavior as an attempt to convince staff members of his heterosexuality and to use denial to avoid dealing with his situation. She did not follow up on Mr. M's remarks about coming out to his family. Within one week, Mr. M's respiratory status worsened and he was transferred to the intensive care unit, where he was placed on a respirator. At this time, Mr. M's wife asked to meet with Mrs. S, and Mrs. S, realizing that she did not know what to say to Mrs. M, requested consultation from her supervisor.

With the help of consultation, Mrs. S was able to examine objectively the staff's reaction and understand their sense of helplessness to change the course of the disease and to focus on what could be changed—Mr. M's so-called denial. Also, consultation clarified that Mrs. S's inability to control her feelings consciously impaired the accuracy of her assessment of Mr. M's situation. By focusing on his homosexuality, Mrs. S failed to assess correctly Mr. M's fear of abandonment and need for closeness. In consultation, she was able to explore her feelings regarding marital fidelity and homosexuality and to explore her fear of touching Mr. M and possibly "catching" AIDS. Because it was unusual, under the circumstances, that Mrs. S did not contact Mr. M's wife and family, she also explored countertransference issues, such as anger, homophobia, and guilt for the "secret" she shared with Mr. M regarding his affairs. It became clear to Mrs. S that her countertransference reactions inhibited her from working effectively with either the staff or with Mr. M.

PROFESSIONAL SELF-AWARENESS

Countertransference issues can be intense for the practitioner who encounters the person with AIDS. Often these issues are disguised and are experienced as anxiety, guilt, despair, indifference, or curiosity. The urge can be great to abandon objectivity and compassion and to succumb to hysteria.

Countertransference occurs on different levels for different reasons. It can be client induced or worker induced. Methods for dealing with countertransference reactions include recognition of the value of these reactions in guiding the therapeutic process and willingness to monitor these feelings on a continuous basis. The authors suggest the following to monitor and deal with countertransference:

1. Understand the countertransference issues that are likely to occur in working with a person who has AIDS and how these issues may be disguised.

2. Identify areas of personal vulnerability to countertransference issues.

3. Educate and sensitize oneself to the issues concerning AIDS and to the lifestyle of the person with AIDS.

4. Practice self-awareness by the use of process recordings, tapes, role playing, or other methods to identify countertransference issues.

5. Practice self-control of countertransference reactions.

6. Identify one's limitations and learn when and how to use supervision.

7. Construct a peer-support system with other practitioners who work with persons with AIDS to identify issues and to alleviate guilt when negative feelings are acknowledged or made conscious.

8. Reach out to homosexual health care providers to get facts and clarification when confused.

9. Seek consultants who are sensitive to this patient population.[22]

The role of the social work practitioner in the AIDS epidemic is vital and still evolving. However, assisting the person with AIDS and the health care system involves a large component of education as well as support. This role can be a challenge, but one that can be approached effectively only after we, as professional caregivers, first take stock of ourselves and address our own countertransference responses when working with this population.

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Briefly Stated

Voluntary Testing for HIV Antibodies among Clients in Long-Term Substance-Abuse Treatment

Robert P. Galea, Benjamin F. Lewis, and Lori A. Baker

Acquired immune deficiency syndrome (AIDS) currently is among the foremost health concerns in the United States. Since the first cases of AIDS were reported in 1981, 56,212 cases of the disease have been reported to the Centers for Disease Control (CDC); consistently, one-fourth of those cases, or 13,881, have been diagnosed in individuals who abuse drugs intravenously.[1] Although sexually active homosexual and bisexual men continue to compose the largest group of individuals at risk for AIDS, totaling 66 percent of all reported cases, research suggests that intravenous drug abusers with human immunodeficiency virus (HIV) infection may be a critical link for the transmission of the virus to the general heterosexual population.[2] Fifty percent of 897 cases of pediatric AIDS have occurred in children who had at least one parent who abused intravenous drugs; 73 percent of the 2,233 cases of AIDS in heterosexuals involved transmission of HIV from an intravenous drug abuser to a spouse or lover.[3] The impact of intravenous drug abusers on the spread of AIDS to other heterosexuals may be greater in the future, especially because many drug abusers work as prostitutes to finance their addiction.[4]

Voluntary Testing

The threat of HIV infection, AIDS-related complex (ARC), and AIDS in members of this population pose special problems for residential substance-abuse treatment programs and other facilities that treat intravenous drug abusers. Although most treatment programs lack the medical facilities to care for clients with ARC or classic AIDS, it is likely that the increased availability of HIV antibody testing in such programs will reveal a significant percentage of HIV-positive, asymptomatic clients enrolled in substance abuse treatment. Currently, the rate of HIV seropositivity among intravenous drug abusers in metropolitan New York and northern New Jersey is between 50 and 60 percent.[5] While seropositivity rates for HIV vary in other parts of the country,[6] it is not unreasonable to assume that, in areas with numerous cases of HIV infection, ARC, or AIDS, one out of every two intravenous drug abusers receiving treatment already may have been exposed to HIV.[7]

Drug treatment professionals confronted with cases of asymptomatic HIV infection in their client populations may need to consider, first and foremost, infection control policies. Such policies protect HIV-negative clients and staff and, perhaps more critically, HIV-positive clients, who may be more susceptible to a variety of infections due to their compromised immune status.

In addition, there are numerous psychosocial issues involved in the treatment of intravenous drug abusers with asymptomatic HIV infection. The diagnosis of HIV infection is, by its very nature, ambiguous, because knowledge is still limited regarding the likelihood of progression from HIV infection to ARC or AIDS. Estimates on the likelihood of developing AIDS in HIV-infected individuals vary from 20 to 60 percent. One study demonstrated that 36 percent of subjects with HIV infection developed AIDS over a period of 72 months.[8] The HIV-positive diagnosis, therefore, may be particularly anxiety provoking, and may undercut the commitment of intravenous drug abusers to remain in treatment. Clearly, it is critical that HIV-positive clients remain in treatment, because a return to drug abuse is likely to lead to transmission of the virus to others, as well as to poor health and further exposures to HIV for the seropositive individual—two factors that might exacerbate the course of the illness.[9]

In response to a growing awareness of the spread of HIV among intravenous drug abusers, a comprehensive substance-abuse treatment program located in Westboro and Worcester, Massachusetts began voluntary HIV testing of clients in its residential, detoxification, and methadone services facilities as part of an ongoing effort to integrate AIDS education and risk assessment into the overall treatment program. Ninety-eight percent of clients undergoing treatment request HIV antibody testing, with a current seropositivity rate of approximately 18 percent.

To ascertain the impact of an HIV-positive test result on client attitudes and commitment to treatment, the authors instituted a six-week series of discussion groups for seropositive clients receiving treatment in the program's residential facility. Although the purpose of the group was informational rather than therapeutic, it also served as a support group for the HIV-positive clients, who were still a minority in the client population. Clients were queried regarding their initial reaction to the HIV-positive test result, attitudes toward health issues in general and HIV infection in particular, the impact of the positive result on relationships with spouses or significant others, their views about the relevance of substance abuse treatment, and their fears of physical and social decline and ostracism surrounding the HIV-positive test result. Clients also were asked their opinions as to the potential efficacy of various modes of education for drug abusers "on the street" regarding AIDS prevention, such as the distribution of clean needles and bleach, and community outreach efforts.

HIV-Positive Discussion Group

As of summer 1987, seven clients in the residential program tested positive for exposure to HIV; all but one are asymptomatic. All of the clients had entered treatment before testing positive and voluntarily decided to take the HIV antibody test when it was made available by the program. Of the seven, one left treatment within a month after a positive HIV test result and fatally overdosed shortly thereafter. Another of the seven HIV-positive clients worked full-time outside the program, and was unable to participate in the group.

The five clients who participated had been in treatment and aware of their HIV-positive status for varying amounts of time. One client, having tested positive for HIV 10 months earlier, had completed the residential component of the program and was receiving treatment as an outpatient; another had been in treatment for 10 months, and had tested positive for HIV exposure six months before inception of the discussion group; two had been in treatment for four months and aware of their positive test result for three months; and one had been in treatment for seven months but knew of the HIV-positive diagnosis for only one month. Three of the clients were male, including one Hispanic; two were female, including one black. All clients were native to the Boston–Worcester areas, with the exception of one client, who was from the metropolitan New York area.

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Client Reactions: Testing Positive

At least two of the five clients in the discussion group cited anxiety regarding AIDS as a significant factor in choosing to enter substance abuse treatment. Both of these clients reported virtually certain exposure to the virus—one through a sexual relationship with an individual subsequently diagnosed with AIDS, the other through the sharing of needles with such an individual. Despite their knowledge of their risk for HIV exposure, however, none of the clients had been tested for AIDS before entering treatment.

All of the clients reported denial and anxiety as their initial reaction to the HIV-positive test result. Although they knew their behavior placed them at risk for AIDS, some group members reported they felt they were immune to AIDS, as well as to hepatitis (another disease common to intravenous drug abusers).

Two of the five clients reported a sense of "my time being limited," even though neither had experienced any symptoms of ARC or AIDS. Also mentioned relative to time limitation was the desire to spend more time with family members or, alternatively, "to run—to be out around people who didn't know me."

The clients who had been aware of their positive test result for the longest periods of time (10 months and six months) reported more feelings of depression, health-related anxiety, and anger. For example, they were more likely to worry that the symptoms of a common illness, such as a cold, might signify the start of an ARC- or AIDS-related infection, although such symptoms would have been unremarkable before the HIV-positive test. Their feelings of anger were sometimes directed toward health-care providers who were unable to cure AIDS, or to answer their questions adequately. One client said she felt that "[her] life is being toyed with."

Although only one of the clients in the group had experienced any symptoms of ARC or AIDS, and none was diagnosed as having either ARC or AIDS, their reactions to the HIV-positive test result mirror reactions found in psychiatric consultations with patients diagnosed with AIDS These reactions include depression, anxiety, feelings of being "experimented on," and a sense of "unfinished business" with family and friends.[10] Additionally, depression among HIV-positive but asymptomatic clients has been associated with the effects of the AIDS virus on the central nervous system were thought to be before the development of opportunistic infections.[11]

Client Attitudes toward Health

Intravenous drug abusers have been noted often for their lack of concern with health, both their own and others.[12] Although the addicts' response to HIV has begun to contradict this assumption,[13] it generally is true that drug abusers often are in poor health because of their addiction. They also are accustomed to observing poor health in members of the social network within which they may share needles. Several of the early symptoms of ARC and AIDS, such as lymphadenopathy, weight loss, fatigue, unexplained fevers, and night sweats, also are common among intravenous drug abusers who do not test positive for exposure to HIV.[14] The indifference of intravenous drug abusers toward health issues was well-illustrated by one of the clients in the HIV-positive group, who indicated that he had shared needles with his sister before entering treatment, despite the fact that she was ill and he suspected she might have AIDS—a suspicion that was confirmed later. Another client admitted that she would have "picked works up off the ground and used them" if she were desperate to "shoot up," despite the risk of exposure to HIV.

Because of the positive test result for exposure to HIV, health became a major concern for all of the clients in the group. Certain attitudes toward health were associated with the length of time clients had been aware of the positive diagnosis. For example, those who most recently had tested positive were concerned especially with issues such as exercising and eating right; they indicated, in particular, the hope that better health habits might delay or prevent the development of ARC or AIDS. These clients initiated personal fitness programs, such as jogging, exercising, or giving up smoking. They also reported instances of "self-testing" their endurance—working harder or staying up later than usual. "When I'm sick I won't lay in bed. I have to get up and keep moving—I'm not going to slack off," one of the clients noted.

The client who had tested positive six months earlier, while acknowledging that he had passed through a stage of self-testing, said he no longer tended to test the limits of his health. Rather, he had begun to take special precautions to guard his health, such as eating well and getting eight hours of sleep every night. Rather than pushing himself, when he felt sick he was likely to rest.

A focus on anxiety and depression regarding specific symptoms was typified by the one client, a female, who had tested positive 10 months earlier. Her depression may have been exacerbated by a long series of infections and poor health, which had, nonetheless, not been diagnosed as ARC or AIDS. Unlike the other clients, she often seemed preoccupied with death as a result of HIV infection, and she was less motivated to pursue healthful changes in exercise and diet. She reported being tired of people urging her to push herself to be more active and less depressed.

Significant Others

The increased concern with health extended to the spouses, lovers, and friends of the HIV-positive clients. Informing spouses and lovers of the HIV-positive diagnosis was a major issue for several members of the group, and others also spoke of the difficulty of contacting persons with whom they shared needles whom they also might have exposed to the virus.

Although the clients were receptive to information about safe sex, actual implementation of safe sex precautions, such as use of condoms, was more ambiguous. Male clients admitted to feeling uncomfortable with the use of condoms—an especially major issue for group members who had progressed in treatment to the point where they could socialize outside the program. One of the female clients admitted to the group that she had sexual intercourse with her boyfriend and did not insist on safe sex precautions, despite her longstanding knowledge of her HIV infection. The reluctance of intravenous drug abusers to alter their sexual behavior has been noted before,[15] along with the observation that they may be more likely to change their behaviors concerning sharing and sterilizing needles than to use safe sex measures.

Clients often mentioned guilt feelings associated with the possibility that they could have transmitted HIV to others. The attitude of family members also was problematic for some group members. Those who already had been estranged from parents or spouses because of their drug abuse feared further rejection because of the positive test for HIV exposure. In general, the level of knowledge about AIDS was lower among clients' family members than among their peers and counselors in the treatment community, with concurrently higher levels of prejudice and fear. Clients spoke of having to educate members of their family about HIV transmission, often at the same time that they told parents or spouses about their own positive test result.

In fact, such fears of rejection and abandonment are realistic ones. Previous observations have shown that HIV seropositive individuals, as well as those with ARC or AIDS, suffer from a considerable degree of social isolation.[10]

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Public Reactions to Testing HIV Positive

Clients' concerns with the negative reactions of others to their HIV-positive status extended beyond spouses and families to include less intimate peers—for example, peers within the drug treatment program, co-workers, and, more broadly, society in general. Their comments indicated they were well aware of the prejudice, hostility, and rejection they might face outside of the treatment program.

Even within the program, the clients mentioned some negative reactions to their HIV-positive status, although the treatment community in general was characterized as supportive. Sometimes, clients mentioned that new admissions to the program were hostile about interacting or sharing sleeping quarters with them, because of their HIV-positive status. They felt like they were "polka-dotted," (that is, different from their peers). Two clients said that their peers made it difficult for them to feel sick—for example, if they stayed in bed to recover from a cold, they were accused of being hypochondriacs or "wanting to be babied" because of their positive test. Another client mentioned being aware of "buried attitudes" in the program that made him feel awkward and oppressed about certain individuals. However, all of the clients also mentioned demonstrations of support from both their peers and staff members that made the residential program a safer environment than the outside world.

Those clients who worked or had other contact with individuals outside the residential program were acutely aware of perceived rejections based on their HIV-positive status. One client, for example, reported that nurses at a local hospital wore gloves to give her a chest X ray—an unnecessary precaution. Another client who participated with the authors in an AIDS conference observed a conference sponsor taking special precautions to dispose of a can of soda from which the client had been drinking. Such instances contributed to a sense of ostracism and feeling different from others regarding their HIV-positive test.

Client's Views: The Value of Treatment

High rates of recidivism are common in all modalities of substance abuse treatment; this is especially true of long-term residential treatment. Observation of dropout rates in long-term residential therapeutic communities has shown six month retention rates of between 25 and 30 percent, with the greatest rate of dropout within the first three months.[17] At this particular treatment program, between 50 and 60 percent of all clients admitted to the long-term residential program leave treatment within the first two months. The percentage of dropouts was significantly smaller among HIV-positive clients (14 percent versus 60 percent).

Clients in the HIV-positive group verbalized a high degree of commitment to treatment; their addiction was perceived as more dangerous in the context of their HIV seropositivity. Although they sometimes admitted feelings of discouragement about remaining in treatment, they characterized a return to drug abuse as suicidal; all believed that they would develop AIDS within a few months if they returned to their previous lifestyle.

For this first group of clients, a positive test was a strong motivator for staying in treatment. Group members commented that "I needed to know I tested positive to go through this program," or "If I hadn't tested positive, I would probably manipulate myself into going on a few more 'runs.' "

Stopping the Spread of AIDS: Client Opinions

Methods of slowing the spread of HIV among intravenous drug abusers have been the subject of considerable public debate. One option in particular, the dispensing of free, clean needles to lessen the sharing of needles among addicts, has been regarded as controversial because it appears to encourage drug abuse.[18] Other methods, such as outreach programs to teach drug abusers how to sterilize their works, are less controversial. The clients in the HIV-positive group were asked their opinions on the potential effectiveness of both methods to slow the transmission of HIV among intravenous drug abusers.

The sharing of needles has been characterized as a ritual form of deeply ingrained social interaction that is important to the drug abusing subculture.[19] If so, the sharing of needles may be difficult to discourage, even with the availability of free needles. However, clients in the discussion group denied a strong social motivation for sharing needles. Rather, they said the sharing of needles is common because addicts are reluctant to spend their drug money to purchase new needles. In fact, they said, the sharing of "works" is disliked by most addicts because it necessitates a period of waiting before they can "shoot up." Free, clean needles, they said, probably would be utilized by addicts, because the waiting is eliminated.

Clients also were enthusiastic about community outreach education programs and the distribution of bleach to addicts "on the street." Several said they would be willing to participate as educators in such a program, especially in neighborhoods with which they are familiar.

Discussion

Among this small sample of clients, the positive test for exposure to HIV enhanced, rather than undercut, the effectiveness of long-term residential substance abuse treatment. This enhancement is manifested most clearly in the low drop-out rate among HIV-positive clients as contrasted with the general client population, especially during the first three months of treatment, when drop-out rates are highest. Other obvious behavioral changes associated with the HIV-positive test result included concern for health and involvement in and commitment to the day-to-day workings of the therapeutic milieu—such as leading educational seminars, establishing discussion groups, and participating in the orientation of new clients. The HIV-positive clients also expressed an enhanced concern for the health of their loved ones, guilt associated with the possibility of having transmitted HIV either sexually or through the sharing of needles, and a transition in values regarding their responsibilities toward their families and themselves. In discussions with these clients, the authors discerned a dialectic of "morality vs. mortality"—activities deemed good by society, such as work, interaction with the family, health-promoting activities, and educating or helping others were regarded by the clients as part of an overall life-style change capable of delaying or altogether preventing the progression of their HIV infection to ARC or AIDS. The ambiguity within the medical profession concerning the meaning of exposure to HIV bolsters the hope that such a change in life-style may be a significant factor in the outcome of infection with HIV.

The conscious sense of the clients' change in values, while beneficial to the continuation of their treatment, also served to mask partially the feelings of fear and anxiety caused by their HIV-positive status. Clearly, the clients' comments showed that they were aware of the difficulties they would face once outside the therapeutic community, including possible physical illness, unemployment, and rejection by spouses or families. Their investment in the structured activities and supportive social networks of the program allowed them simultaneously to deny and positively channel some of their fears regarding HIV, ARC, and AIDS.

Although the results of discussions with a small group of HIV-positive clients are not generalizable to the overall population of HIV seropositive intravenous drug abusers undergoing long-term residential treatment, the attitudes of these clients do indicate that testing for exposure to HIV among members of this population may prove beneficial to treatment outcome. However, such testing should be implemented within treatment settings where knowledge about HIV has been disseminated among staff and clients to allow a supportive reaction to the presence of HIV-positive individuals. It also is important that clients be provided with intensive pre- and posttest counseling and access to support groups throughout the course of their treatment.

The comments of these clients support the emerging opinion among researchers that intravenous drug abusers are receptive to AIDS education and to the use of simple procedures for the sterilization of shared needles. However, members of this group were reluctant to discuss and implement safe sex precautions. Given the critical role played by intravenous drug abusers in the heterosexual transmission of HIV, education to enhance changes in sexual behavior must be implemented in conjunction with that emphasizing the sterilization of drug paraphernalia.

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Positive therapeutic Effects of Intercessory Prayer in a Coronary Care Unit Population

The therapeutic effects of intercessory prayer (IP) to the Judeo-Christian God, one of the oldest forms of therapy, has had little attention in the medical literature. To evaluate the effects of IP in a coronary care unit population, a prospective, randomized, double-blind protocol was followed. During ten months, 393 patients admitted to the unit were randomized after signing informed consent to an intercessory prayer group (192 patients) or to a control group did not. At entry, x2 and stepwise logistic analysis revealed no statistical difference between the groups. After entry, all patients had follow-up for the remainder of the admission. The IP group subsequently had a significantly lower severity score based on the hospital course after entry ($P<.01$). Multivariant analysis separated the groups on the basis of the outcome variables ($P<.0001$). The control patients required ventilatory assistance, antibiotics, and diuretics more frequently than patients in the IP group. These data suggest that IP to the Judeo-Christian God has a beneficial therapeutic effect in patients admitted to a coronary care unit.

Legal Limits of AIDS Confidentiality

Bernard M. Dickens, PhD, LLD

THE IMPACT that the acquired immunodeficiency syndrome (AIDS) is having on social relationships finds expression in legal relationships. The medical or health care setting is only one of many in which legal rights, duties, and powers are affected by individuals' liability to transmit or to suffer from human immunodeficiency virus (HIV) infection.[1] Medical diagnosis, care, and counseling of patients with AIDS certainly raise crucial concerns of health care professionals, allied health workers, and patients. Their concerns are, however, representative rather than exhaustive of those felt throughout society.

Fears of HIV infection contracted in the workplace are unreasonable, but nevertheless commonplace, in all but a few occupations. Where fellow employees risk wounds that bleed, for instance, colleagues may demand protection. In schools, teaching and auxiliary staff may fear exposure to children's body fluids, more frequently passed, no doubt, by younger children, and the same is true in day-care centers. Proximately shared housing may cause occupants to fear their neighbors' infection, and partners in recreational activities, particularly body-contact sports that involve the shedding of perspiration and blood, may have additional grounds for unease. In commerce, insurance companies have publicized their apprehensions of unknowingly writing life or health insurance policies for AIDS sufferers, which may upset their balance of expenditures and premium income.

Health care professionals, employers, fellow employees, educators, and neighbors may claim legitimate interests of self-protection in knowing who is liable to transmit HIV. They may demand disclosure of the identities of persons with AIDS, AIDS-related complex (ARC), or positive test results for exposure to HIV. Hospital and public health officers then come under pressure to serve these individuals' asserted rights to know, even at the cost of compromising their patients' right to confidentiality.

The response from professionals has varied. Some critics point out that disclosure of HIV-antibody test results would be dysfunctional if it caused those whose blood tested negative to be presumed not infected, since the test may have been conducted during incubation of the AIDS virus. Hence, everyone must initially be presumed infected irrespective of testing and test results. Others, particularly in the public health field, contend that liability to disclosure of identity would deter from submission to testing members of high-risk populations who represent the greatest risk of spreading HIV infection. Almost all critics point to laws, however, that mandate the maintenance of strict confidentiality of medical data. Legislation, often detailed in subordinate regulations and enforced in litigated cases, shows the law's determination to reinforce ethical duties of maintaining confidentiality of medical information by legal sanctions, both penal and compensatory.

It will be argued herein, however, that, in the context of HIV infection, the law's protection of medical confidence is frequently illusory. It will be shown that while some laws appear to require and provide secrecy of medical data, others compel disclosures; moreover, justifications and excuses of breaches of confidentiality exist under transcending legal doctrines. It is concluded that the most effective use of legislation is not simply to seek to enact further protections of confidentiality of data, which would be subject to the same exceptions, but to reinforce laws against discrimination on grounds of an individual's affliction with AIDS, ARC, or HIV infection.

THE DUTY TO WARN

Liability to transmit HIV infection represents a danger to health and to life itself. The law has priorized preservation of medical confidentiality and preservation of human life, not in the context of AIDS but in a patient's anticipated potential to endanger another person's life. In the widely discussed California Supreme Court case of *Tarasoff v Regents of the University of California*,[2] the defendants argued, inter alia, that a legal duty of confidentiality prevented a warning from being given to a person (or to his or her family) who was predicted to be at risk from possible attack from a mental health patient. Legislation often permits psychiatrists, psychologists, and comparable mental health professionals to enjoy the privilege to preserve patients' confidences, because disclosure would jeopardize therapeutic relationships that are in the public interest to foster. The defendant invoked both law and policy to support silence in the face of diagnosed danger to an identifiable victim. The Court observed that: "We recognize the public interest in supporting effective treatment of mental illness and in protecting the rights of patients to privacy, and the consequent public importance of safeguarding the confidential character of psychotherapeutic communication. Against this interest, however, we must weigh the public interest in safety from violent assault."[3]

In priorizing confidentiality and safety, the Court concluded that "the public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins."[4]

The Tarasoff principle, though initially contentious, has spread beyond California and beyond a duty to act in cases where the victim of another's foreseeable dangerousness is known, to those instances in which the victim is not individually identifiable.[5] The principle appears no less applicable to danger by spreading HIV infection than to danger by violence.

Dangerousness is a legal status rather than a psychiatric disposition or a condition of infectiousness.[6] Physicians and related professionals are recognized to have special legal relationships, of a tortious and fiduciary nature, toward third parties they anticipate or reasonably should anticipate being harmed by their patients. Particularly if victims are identifiable, they are owed a duty to be warned. If they are individually unidentifiable, warning to others, such as the police, may be legally required. If legislation mandates preservation of patients' confidentiality, it would probably be read as subject to this limitation, unless the enactment provides otherwise by explicit terms. It is of no consequence that the goal of the mandated protection of confidentiality, namely, to encourage recourse to professional care in the public interest, is thereby compromised.

Accordingly, where general legislation appears to offer

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HIV-infected patients protection against disclosure of their condition, it may not prevail over a contending claim that known potential victims of that transmissible infection, such as spouses, are entitled to receive information of the source and nature of the risk to their health and lives. If potential victims are unidentifiable, disclosure of infected persons' names to public health authorities would be justified where not expressly mandated by law, and the police powers of states would be applicable, notably to detain under quarantine provisions.[7]

THE POWER TO WARN

When legislation has created no duty to give information about an HIV-infected person's identity or threat of danger and when tort law and fiduciary responsibilities similarly provide no duty to warn, the law may nevertheless recognize a power to warn that is exercisable in good faith. It has been considered justifiable, for instance, to violate medical confidentiality to give warning of a patient's propensity to bring distress to an intended marriage partner.

In *Berry v Moench*,[8] the physician was a psychiatrist who disclosed his patient's diagnosis to inform the parents of the patient's fiancee. The patient sued for libel, and the psychiatrist pleaded alternative defenses of truth and conditional privilege. Defamation law concerns communication of injurious falsehood, whereas breach of confidentiality concerns improper communication of truths. The court addressed whether liability would follow were the physician's revelations untrue and concluded that it would not, provided that the physician was neither malicious nor careless. It was observed that "...the responsibility of the doctor to keep confidence may be outweighed by a higher duty to give out information, even though defamatory, if there was [*sic*] a sufficiently important interest to protect.... Where life, safety, well-being or other important interest is in jeopardy, one having information which could protect against the hazard, may have a conditional privilege to reveal information for such purpose, even though it may be defamatory and prove to be false."[9]

This approach seems applicable to disclosure of HIV positivity and covers conscientious disclosure of a test outcome even when it proves to be a false-positive result. More restrictively, however, the Court observed that disclosure of even truthful information may not be permissible in defamation law if it is excessive. The following criteria were established to determine whether the privilege of disclosure exists: (1) the physician must use good faith and reasonable care to tell the truth; (2) the information must be reported fairly; (3) only necessary information must be given; and (4) publication must be limited to those persons necessary for protection of the threatened interest.[10]

Legislation mandating preservation of confidentiality of persons who are HIV positive may accordingly be subject to an implied exception allowing a limited power of disclosure when necessary to protect "life, safety, well-being or other important interest."[9] This recognition of necessity in civil law mirrors criminal law's accommodation of the necessity defense.

CRIMINAL LAW

Criminal law has a long tradition of tolerating violations of legal prohibitions, provided that they were inspired by the motive to save human life. Indeed, provided that proper procedures of decision making have been applied, the courts may accept the defense of necessity to save human life, of a person in particular or of persons in general, for even the egregious crime of willfully causing death itself.[11] On this scale of values, it is evident that willful violation of laws mandating protection of medical confidentiality committed to reduce individual risk of exposure to HIV infection can be legally defensible. The rate of progression to AIDS of those who are infected with HIV is not established, but for purposes of law, a claimed motive to protect against HIV exposure, to save life, may seem credible.

Consistent with the criminal law principle that defendants are judged according to the facts as they see them, including mistaken facts, the initial question is whether the proven violator of confidentiality sincerely perceived a lethal menace. This is a subjective question resolved by a subjective finding, but a defendant's assertion of fact is reinforced where the claimed perception is objectively reasonable.[12] Determination of a lethal menace from transmission of HIV may seem reasonable, either by virtue of scientific data about the spread of the infection or by the strength of popular belief.

The second question is whether, accepting the facts as perceived, the defendant's priorization of values, setting the interest sought to be protected (saving human life) against the value willfully sacrificed (confidentiality), is objectively proportionate. Courts themselves have been willing to subordinate medical confidentiality to protect potential victims' lives and health. Courts also require, however, that the means chosen be the minimum necessary under the circumstances.

This objective priorization and the principle of proportionality are challenged by legislation enacted expressly for the purpose of protecting from disclosure medical evidence of HIV infection. The political process resulting in such legislation offers a clear statement of prevailing social values. Courts may nevertheless find that a defendant's sense of necessity to save life invokes pervasive values that the legislation does not intend to displace because they concern not just the transitory preference of public health policy but also the enduring sentiments of the people concerning the sanctity of life. Accordingly, AIDS legislation reinforcing confidentiality may have difficulty in excluding charged defendants' reliance on the defense of necessity to breach confidentiality.

Criminal process provides further exceptions to legislation limiting identification of HIV-infected persons. Some who have risked transmission of the virus to others, for instance, through unprotected sexual intercourse, have been charged with commission of offenses. Attempted murder charges have been considered.[13] For instance, in South Carolina an infected detainee who bit his captor was charged with assault with a deadly weapon (*New York Times*, June 25, 1987), while in Los Angeles a man was charged with attempted murder for knowingly selling his HIV-infected blood for transfusion (*New York Times*, June 30, 1987).

Whatever the outcome of such cases, they are part of criminal process and, except in the case of juveniles, they attract news media coverage that names the defendants (as happened in the South Carolina and Los Angeles cases). Constitutional protections of freedom of the press justify or at least excuse publication of names and specific medical histories of HIV-diagnosed persons arrested for and charged with committing offenses. This marks a further limit of confidentiality laws.

POLICE POWERS

In the Tarasoff case,[5] the patient's identity and anticipated pathologic behavior were communicated to campus police. Although the defendants made a spirited claim that they were mandated to protect medical confidentiality despite considerable danger to an identifiable prospective victim, they never considered that disclosure to the police was improper. The police are commonly presumed to be within the charmed circle of those entitled to be informed of anticipated injuries that medical patients, due to their conditions, may cause others.

Public health authorities share with mental health authorities[14] a function to discharge the state's policing responsibility for public protection against dangerous persons and may lawfully be given information appropriate for the discharge of that function. Furthermore, legislation often mandates that, notwithstanding confidentiality duties owed by others, information be given to these authorities. Cases of AIDS, as defined by the Centers for Disease Control, Atlanta, are compulsorily reportable in every state, and a number of states require reporting of positive HIV-antibody test results. In addition, general provisions that do not specify HIV infection as notifiable require reporting of incidents related to listed diseases, including AIDS.[15]

Constitutionally protected rights of privacy generally limit information that policing agencies can demand, but these rights may be inapplicable to homosexual conduct.[16] General legal requirements to report AIDS or HIV infection would appear constitutional under the US Supreme Court's doctrine stated in *Whalen v Roe*[17] if (1) the information were reasonably related to a valid public health purpose; (2) the information were limited to public health departments; and (3) there were adequate statutory confidentiality protections in place.

Like other state policing services, public health agencies are inclined to protect their informants' identities from disclosure, but those to whom they legitimately release information may be under no reciprocal legal or enforceable duty of confidentiality.

The US Supreme Court's acceptance in *Whalen v Roe* of governmental maintenance of personally identifiable records of confidential medical information—provided that adequate protections exist against improper disclosures—was given soon after the Tarasoff decision in California. The Supreme Court acknowledged that public disclosure of patient information could occur in a number of deliberate and negligent ways. The Court was persuaded, however, that the legislated program of data storage in question did not, on its face, pose a sufficiently grievous threat to patients' interests in nondisclosure of private information and in making important health care decisions without state intervention to establish a constitutional violation. Public health considerations were thereby balanced favorably against concerns to protect the highest possible level of personal confidentiality.

Commentators and critics have pointed to the failure of historic public health statutes currently in force to reflect modern conceptions in science and law and to the extent to which complacency about the exercise of compulsory powers has been displaced by the AIDS epidemic.[18] Agencies themselves may be adequately vigilant about confidentiality of data compulsorily submitted, but when sexual contact tracing is undertaken, information may pass to persons not necessarily bound by the same standards. Thus, information can seep into general circulation and be beyond protection. When the physician and manager of the late entertainer Liberace preserved confidentiality of the cause of death, members of the news media voiced their suspicions of deceit and forced a public officer's disclosure of the medical facts, notwithstanding California's legislation of provisions for confidentiality.

CONCLUSION

Reliance cannot be placed on the law to restrict breaches of confidentiality of HIV-infected persons' identities. Too much in the law itself compels, justifies, and excuses disclosure of information. Victims of the disease exposed to stigmatization, humiliation, ostracism, and even physical assault of their persons and homes cannot confidently seek legal remedies for harmful disclosures when the law requires or tolerates publicity of their medical condition. Legislative planning is better devoted not simply to enacting further confidentiality provisions but also to minimizing discrimination against infected persons in such areas as employment, housing, education, insurance, and access to medical care once their condition becomes known.[19]

Legislation proposed by Senator Kennedy and Representative Waxman to amend the Public Health Service Act to protect persons with AIDS or related conditions points in the right direction. Applicants for grants to support counseling and testing programs regarding HIV infection must agree to comply with federal, state, and local laws aimed to ensure confidentiality of information and records of those counseled or tested. To the extent permitted by relevant law, opportunities should be offered for anonymous counseling and testing. Unjustified breaches of confidentiality attract civil monetary penalties, civil claims for damages or other remedies, and criminal penalties. Emphasis is given, however, to the prohibition of discrimination against those who are, or who are regarded as being, infected with HIV in employment, housing, public accommodations, and governmental services. Discrimination is similarly prohibited in the provision of benefits under any program or activity that receives or benefits from federal financial assistance. Discrimination attracts liability to civil monetary penalties and civil causes of action, including prohibitory injunction. The coupling of confidentiality protections to provision against discrimination acknowledges that reliance cannot be placed on confidentiality provisions alone.

Patients with AIDS exist preponderantly among populations of homosexual men, drug users, and prostitutes who already face considerable discrimination. Their activities are frequently criminal, and specialized police forces such as morality and antidrug squads focus on reducing and frustrating pursuit of these practices. Aware of their liability to suffer discrimination, members of these populations will not seek testing or help from public agencies unless reassured that they will not be further isolated by hostile responses and loss of liberties.

The US Supreme Court's finding that a person with tuberculosis is handicapped within the meaning of the federal Rehabilitation Act[20] provides grounds to believe that persons with AIDS, ARC, and HIV positivity are similarly handicapped. They are accordingly protected against discrimination in federally funded programs. Achievement of public health goals of containing the spread of HIV infection, by reaching high-risk populations and affording them education and means to protect themselves and others, will not be advanced simply by enacting promises of confidentiality. These promises are too liable to prove flawed and illusory, because of doctrines and dispositions of the law itself. More is likely to be gained by enacting and enforcing protections against discrimination in crucial areas for those affected persons whose identities are likely to become known.

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SPECIAL ARTICLE

THE CASE FOR WIDER USE OF TESTING FOR HIV INFECTION

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EIGHT years into the most serious pandemic of infectious disease in modern history, we possess the technology and resources to test for evidence of human immunodeficiency virus (HIV) infection accurately and economically. Yet there has been great reluctance on the part of the federal government and medical leaders to advocate extensive use of HIV testing as a public health measure. We believe that a very strong case can be made for wider HIV testing.

Most discussions of HIV testing reach a conclusion on whether testing should be encouraged, at least in populations in which the prevalence of infection with the virus is high. Although Weiss and Thier in their recent *Journal* editorial[1] found no basis for testing beyond screening before blood and tissue donation, most national bodies have favored the broader use of HIV testing. The Committee for the Oversight of AIDS Activities of the Institute of Medicine favored "expanded voluntary testing combined with counseling of all those whose behavior may have put them at risk for exposure to HIV."[2] Likewise, the Presidential Commission on the Human Immunodeficiency Virus Epidemic recommended that "people who fall into any of the [high-risk] categories should seek testing and counseling services from their physician or public health agency, regardless of the presence or absence of symptoms."[3] Even more strongly, the Centers for Disease Control (CDC) has endorsed routine testing of persons who may have a sexually transmitted disease, intravenous drug abusers, and others who consider themselves at risk of HIV infection.[4] The Canadian National Advisory Committee on AIDS has also recommended voluntary HIV testing in persons whose histories put them at risk.[5] In endorsing HIV testing, none of these groups has presented a rationale beyond the reduction of transmission of HIV. We offer here additional public health reasons for much wider use of HIV testing, and we argue further that persons infected with HIV can gain important, direct health benefits from learning of their infection as early as possible.

We advocate only voluntary testing, by which we mean that the test must be discussed with the person before testing, and that testing may be refused. Moreover, all HIV testing must be accompanied by stringent institutional and societal safeguards of confidentiality and privacy.[6]

In November 1987, the Public Health Service estimated that there were between 945,000 and 1,400,000 persons infected with HIV in this country.[7] Even to-

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day, most of them do not know that they are infected, although HIV testing has been available for four years. Since September 1985, it has been necessary to report all cases of HIV infection in Minnesota. (This has brought, incidentally, no known harm to those whose infection has been reported.) As of April 1, 1989, there have been 1100 reported cases of HIV infection in addition to 504 reported cases of acquired immunodeficiency syndrome (AIDS). The Minnesota Department of Health estimates that there are between 10,000 and 30,000 Minnesotans infected with HIV (Osterholm MT: personal communication, December 5, 1988). If one uses the low end of this range and allows for substantial underreporting of diagnosed HIV infections, less than 20 percent of Minnesotans infected with HIV know of their infection. The situation in Wisconsin is quite similar: 318 cases of residents with AIDS and an additional 1065 cases of HIV infection have been reported; and an estimated 7000 to 11,000 residents of Wisconsin are thought to have HIV infection (Davis JP: personal communication, April 10, 1989). Nationally, the percentage of persons infected with HIV who know of their infection is probably smaller, because the level of acceptance of HIV testing in the upper Midwest is thought to be relatively high and the prevalence of HIV infection is relatively low. The continuing detection of HIV infection among blood donors (0.043 percent of first-time donors through 1987),[7] applicants for military service (0.15 percent),[8] and Job Corps applicants (0.33 percent)[7] is strong evidence that many — and probably most — Americans infected with HIV are not aware of it, although nearly all infected persons will ultimately report histories that put them at risk of HIV infection. Thus, current efforts to make persons infected with HIV aware of their infection are failing. We argue here that widespread voluntary HIV testing based within the health care system must be promoted nationally to bring us nearer the goal of informing all persons infected with HIV about their condition.

Before focusing on the testing of apparently healthy, asymptomatic persons, we should address two related issues. First, our views on the testing of asymptomatic persons do not apply to the testing of those with symptoms compatible with illness caused by HIV, for whom few would argue with the clinical value of an HIV test. Second, there are several specific clinical situations in which persons without HIV-related symptoms should be tested routinely. The CDC has explicitly recommended that an HIV test be performed in all persons with syphilis[9] or active tuberculosis,[10] because the presence of HIV infection alters the suggested therapy and follow-up. It is, we believe, a logical extension of the CDC recommendation to advocate testing for HIV infection in all tuberculin-positive persons. Although the current policy of smallpox vaccination in U.S. military forces can be questioned,[11] it seems wise to recommend an HIV test before vaccination.[12] Finally, the CDC has also implicitly recommended testing before vaccination in persons in whom bacille Calmette–Guérin vaccine is indicated[13] and — when health care personnel have been exposed to a patient's blood through injury such as a needle stick — explicitly recommended testing the patient for HIV infection.[14]

Benefits for Persons Infected with HIV

We believe that detecting the infection as early as possible can provide substantial, direct health benefits to all persons infected with HIV. Tuberculin skin testing should be performed before a loss of delayed cutaneous hypersensitivity occurs. Although only about 2 percent of all U.S. patients with AIDS contract tuberculosis,[15] those with dormant foci of *Mycobacterium tuberculosis* have a very high risk of active disease.[16] Since a large fraction of the people infected with HIV will contract AIDS, all those with current positive tuberculin tests or reliable histories of positive tuberculin tests should receive preventive therapy with isoniazid, unless there are major contraindications. This therapy should be instituted as early as possible because active tuberculosis may be the first illness caused by HIV and because the presence of other illnesses associated with HIV infection or the administration of other therapies may complicate the administration of isoniazid. Influenza vaccine and pneumococcal polysaccharide vaccine are recommended for all people infected with HIV.[17,18] The recommendation for pneumococcal immunization explicitly states that the vaccine be given as early in the course of HIV disease as possible, to maximize the antibody response. Since patients with AIDS are at an increased risk of sepsis and pneumonia caused by *Haemophilus influenzae* type b[19,20] as well as *Streptococcus pneumoniae*, a similar case can be made for immunization against *H. influenzae*.

The early detection of asymptomatic HIV infection provides an even more important health benefit to those who — because they are unaware of their infection, are incompletely educated about hazardous signs and symptoms, or deny the possibility of contracting HIV-related disease — fail to seek medical attention promptly when symptomatic HIV illness appears. Clinicians experienced with AIDS know well the frustration of encountering persons infected with HIV who have very low numbers of CD4+ T cells and who are seeking medical attention only after months of gradual worsening of HIV-induced symptoms or with advanced opportunistic infection. Clearly, many would have benefited from earlier institution of therapy with zidovudine or a therapy specific to opportunistic infection. Many persons who may be infected with HIV do not fully recognize that HIV infection is a treatable condition. The capacity for denial is sufficiently strong that a far more active approach to HIV testing should be taken than we now have, for timely intervention in a larger number of cases.

Evidence is accumulating that, after initial infection, CD4+ T-cell counts first fall, then remain relatively stable, and finally begin to decrease more rapidly. This last phase is a harbinger of opportunistic infection.[21,22] If the absolute value and the slope of the CD4+ T-cell count are independent predictors of illness induced by HIV, serial monitoring is needed for the best assessment of the severity of HIV disease. We believe infected persons should be seen at least quarterly so that therapy with zidovudine and prophylaxis against *Pneumocystis carinii* pneumonia can begin at the earliest appropriate time. Patients should probably be seen even more frequently until the physician is confident that they will recognize and promptly report subtle symptoms induced by HIV.

If evidence establishes that therapy is indicated for asymptomatic HIV infection, testing will benefit patients in yet another way. Protocol 019 of the National Institutes of Health AIDS Clinical Trials Group, a placebo-controlled trial of zidovudine for asymptomatic HIV infection, could end at any time with a recommendation that all persons infected with HIV should receive zidovudine. We would then confront two problems: the orderly identification of HIV infection in the large number of people at risk for HIV who would come forward immediately, and the timely identification of those who deny to themselves their histories of risk factors for HIV.

Benefits to the Public Health

We believe that a recommendation to undergo HIV testing as part of routine health care would also have important benefits to society. General acceptance of HIV testing would reduce the reluctance to be tested of persons who know they are at increased risk. Taking the test would heighten the sense of vulnerability that is a necessary part of decisions to adopt more healthful behavior.[23] Although there are many sexually transmitted disorders that should convince all persons to avoid unprotected coitus, the fear of HIV infection may foster most powerfully the changes in sexual behavior our society must make. Taking the test would enhance appreciation of the fact that AIDS is a problem that society at large must face. It would help undercut the pernicious we–they mentality that feeds the social stigmatization associated with AIDS and HIV infection.

There has been widespread discussion of the public health benefit of HIV testing — primarily as an adjunct to counseling — as part of the efforts to reduce the transmission of HIV. In their editorial, Weiss and Thier describe this rationale, without detailed analysis, as "unproved."[1] We agree that the available studies are not conclusive, but in the populations studied, HIV testing appears to have reduced unsafe sexual behavior in those infected with HIV.[24-26] The effect of testing on those who are found not to be infected with HIV is admittedly less clear, but it too appears favorable. If one presumes that most people do not want to hurt others and that the gravity of HIV infection is becoming more widely recognized, the beneficial effects of testing should grow with time. In any case, these studies are only indirectly relevant to the context we discuss, because they were limited to homosexual men who volunteered for HIV-related studies, attended counseling and testing centers, or otherwise came forward voluntarily. Such persons had already broken through some of the denial that acts as a barrier to changing their behavior. Our greatest concern is to reach the great number of persons infected with HIV who are not availing themselves of any current options in testing and who are not confronting their risk of HIV infection.

As evidence that identifying persons infected with HIV through more widespread testing would reduce risk through more intensive counseling, we offer the findings of a study in blood donors[27] and our experience with patients with hemophilia. Williams et al.[27] found substantial reductions in unsafe activities — reductions considerably greater than those likely in society as a whole — during the year after blood donors were notified of their infection. Patients with hemophilia are even more relevant to the context we discuss — the widespread testing of persons in the general population receiving health care. Most patients with hemophilia are already under close medical supervision, and because their physicians recognize that their patients are at increased risk of infection with HIV, most patients have been encouraged to undergo testing. There is ample evidence that in spite of general educational messages about their very substantial risk of HIV, many patients with hemophilia engage in unprotected sex.[28-30] Although we know of no systematically collected data on the point, we are convinced that many patients with hemophilia do not begin to pay attention to the risk of sexual transmission of HIV until they are tested. Furthermore, we have found that intensive, repeated counseling, ideally involving the patients' regular sexual partners, is often required to reduce unsafe sexual practices among those whose tests are positive to their current levels, which are still unsatisfactory. Finally, we believe that persons infected with HIV who are tested through the health care system serve as the best starting points for programs to notify sexual partners.

An additional and often overlooked public health benefit of HIV testing is the identification of candidates for research studies of zidovudine and experimental therapies. There has been insufficient recognition of the critical need for research subjects among persons who are potentially infected with HIV. For instance, the AIDS Clinical Trials Group's protocol 019, which is of enormous importance to the million or more asymptomatic persons infected with HIV in this country, will have taken almost two years to complete enrollment. It is preferable to conduct Phase I and II trials of potential agents against HIV in patients who are not taking other antiviral agents, but a large majority of patients with symptoms take zidovudine. The need for asymptomatic people infected with HIV to participate in the initial studies of promising therapeutic agents is urgent. We are in a desperate race against time to develop therapies for those who are now infected with HIV. All persons infected with HIV who want to help fight AIDS should be strongly urged to participate in experimental studies.

Another reason for expanding HIV testing is the potential benefit of zidovudine therapy after exposure to HIV. Eleven cases of occupational transmission of HIV with documented seroconversion have been reported among health care personnel in the United States.[31-33] Additional cases of such transmission have been reported from outside this country[31,34] or without documented seroconversion.[34] Many more such cases have undoubtedly occurred but have not yet been recognized, have not been published because they could not be reliably attributed to exposure on the job, or have not been reported because no formal system of surveillance for occupational transmission exists. Two published reports of experiments with animal models have described the beneficial effects of zidovudine after exposure to a retrovirus. In mice exposed to Rauscher murine leukemia virus, infection was prevented when zidovudine administration lasting 20 days was begun within four hours of exposure, but not when treatment was begun seven days after exposure.[35] In weanling kittens inoculated with feline leukemia virus, zidovudine administration for 42 days prevented viremia when treatment was begun one hour after inoculation, but not when begun seven days after inoculation; treatment that began three and seven days after exposure afforded intermediate degrees of protection.[36] The applicability of these studies to persons exposed to HIV is limited, but we believe that hospitals should offer personnel who have been exposed to the blood or other high-risk bodily fluids of a patient infected with HIV the option of zidovudine prophylaxis paid for by the hospital. However, the potential benefits of postexposure treatment with zidovudine are not sufficient to warrant it in personnel exposed to a patient at low risk whose status for infection with HIV is still being evaluated. If prophylaxis with zidovudine is accepted, it should be initiated as soon after exposure as possible, ideally within an hour, but the assessment of a patient for possible HIV infection in so short a time is logistically very difficult. This is an additional argument in favor of the routine, voluntary screening for HIV in newly hospitalized patients.

Another current issue bears on the testing of hospitalized patients for HIV. The CDC and the Department of Labor have recommended the adoption of "universal precautions" — precautions in the care of all patients, not just those known to be infected with hepatitis B or HIV.[14] Efforts to encourage the careful handling of specimens from untested patients are certainly laudable, because some infectious materials will inevitably be unrecognized as such. But the adoption of universal precautions is sometimes used as an argument against HIV testing, and some hospitals have removed warning designations for patients known to be infectious and their specimens. This approach has been advocated without careful study of whether health care workers are in practice as vigorous in exercising precautions when the patient has no known infection as they are when the patient is known to be infectious. The concept of universal precautions clearly deviates from that of targeted precautions concerning patients with known infection, which has been the approach for the past 20 years to preventing cross-infection and transmission with virtually all other contagious diseases.[37] Universal precautions might provide less protection than routine HIV screening and targeted precautions in hospitals with a low prevalence of HIV and hepatitis B among their patients or in situations — such as certain types of surgery — in which very heavy exposure to blood and a high incidence of percutaneous injury occur.[38] We believe that the effectiveness of universal precautions should be evaluated scientifically. The outcome of such studies may provide a basis for the institution of routine screening of hospitalized patients in at least some contexts.

Benefit versus Harm

Having established that there are personal as well as public health benefits in increasing the percentage of persons infected with HIV who know of their infection, we are still left with difficult issues. Would an extensive HIV testing program based within the health care system have paradoxical effects on public health? Does the diagnosis of an asymptomatic HIV infection constitute a *net* benefit to the infected person?

HIV testing based within the health care system could paradoxically have adverse effects on public health in two ways. It is often asserted that aggressive testing programs could drive underground, or away from the health care system, those who fear or know that they are infected with HIV. We believe those likely to respond in this way are already underground, and every person retains the right to refuse testing. Aggressive testing programs could also lead to the rejection of all efforts at testing, even at centers for counseling and testing. We believe, however, that raising the issue with all patients increases the probability that those who refuse the test in a hospital or office will use such centers.

The disruption caused by a false positive test is uniformly advanced as an argument against the wider use of testing. However, screening with sequential enzyme immunoassays followed by confirmation with Western blot testing according to current, more stringent criteria should produce a false positive test only rarely.[39,40] It must be acknowledged that the studies cited were done in high-quality laboratories and may suffer from spectrum bias.[41] Falsely reactive enzyme immunoassay results might be more common in ill persons[42] than in healthy blood donors or military recruits.

Nonetheless, false positive tests — i.e., screening with enzyme immunoassay followed by Western blot confirmation — occur so infrequently that no large North American population (with the possible exception of blood donors, who are already being tested) is so free of HIV infection that the predictive value of a positive result would be appreciably reduced. The published reports of false positive results of Western blot testing according to modern interpretive criteria[43,44] are subject to criticism: the findings were not derived from population-based studies; they are subject to referral bias[41]; we do not know how representative their specimens are; and their positive results may have been detected on specimens whose enzyme immunoassay screening was nonreactive.

The practical problem in serologic testing for HIV is the indeterminate Western blot test. According to screening of Minnesota blood donors between 1985 and 1988, just under 1 in 1000 uninfected persons will have a repeatedly reactive enzyme immunoassay and an indeterminate Western blot.[42] The specificity of testing for HIV is improving. Current screening of Minnesota blood donors shows that about 1 in 1000 has a repeatedly reactive enzyme immunoassay, and of these, 12 percent have indeterminate Western blots (Jackson JB: personal communication, February 27, 1989). Culture of blood for HIV, now available by mail from laboratories with 98 percent rates of recovery of HIV from asymptomatic persons infected with HIV,[45] can help resolve indeterminate Western blot tests. Polymerase chain-reaction testing will probably further enhance this capability.

How then can persons infected with HIV be harmed by learning of their infection? Most go through a period of intense emotional distress after diagnosis. This period, however, seldom lasts more than several weeks. Since the reality of HIV infection will ultimately make itself known to most or all persons infected with HIV, to put off learning of an HIV infection postpones but does not eliminate the period of anguish. And in any case, the potential anguish should be weighed against the aggregate anxiety of those who know they are at risk yet remain untested. It is tempting to try to shield anyone from harsh and unfair realities, but this somewhat paternalistic temptation runs counter to the prevailing trend toward a patient's right to know, a trend that has arisen in this generation. Part of the physician's responsibility is to be the bearer of bad news.

It could be argued that counseling and testing centers are better able to mitigate the initial distress associated with the diagnosis of an HIV infection. A substantial fraction of HIV testing, however, already occurs in physicians' offices and hospitals,[46] and counseling by a physician with whom one already has an established relationship should be advantageous. Moreover, an extensive program of HIV testing based within the health care system would stimulate physicians to acquire the requisite skills. It has been argued that HIV testing serves the tested best when it is performed in settings that offer anonymity. Although many who would be tested prefer anonymity, it is nonetheless an elusive goal for most persons who find themselves infected with HIV, even while they remain asymptomatic. It is psychologically burdensome to withhold the information from all friends and loved ones. In addition, virtually all counseling and testing centers advise persons infected with HIV to obtain a physician. We believe that persons who do not contact a physician immediately are more apt to delay seeking medical care if HIV-related symptoms occur. Recommendations to inform dentists and other health care workers about one's HIV infection are uniform.

Finally, it can be argued that the benefits to those infected with HIV are outweighed by the potential for discrimination. Most discrimination related to HIV — in the workplace, in housing, in schools, and in society — is irrational, notwithstanding substantial public sentiment[47] to the contrary. Some types of discrimination, although unfair, are understandable in economic terms. An employer motivated by economic considerations will tend not to hire, promote, or specially train infected persons because they are more likely to use sick-leave and health-insurance benefits. Similarly, an insurer will prefer not to offer health insurance to persons with HIV. Because discrimination will subvert the good that wider HIV testing can produce, we must vigorously fight it. Physicians should also fight for society's acceptance of homosexuality[48] and for improved funding for drug abuse treatment and related research. We have a special responsibility to advance these positions because of their importance in the fight against AIDS. In essence, we are arguing that HIV infection should be treated as much as possible like any other infectious disease. We should fight the unfair consequences that interfere with this goal.

ROUTINE SCREENING WITHIN THE HEALTH CARE SYSTEM

We have concluded that HIV testing provides a net benefit both to the public health and to persons infected with HIV. We now turn to the issue of implementing broader testing. We believe that the nation's physicians and other health care providers should assume a much more active role in promoting HIV testing. Before presenting our argument we digress to assert two important underlying premises. We believe that a thorough sexual and drug-use history must be part of any routine health assessment. Patients should find physicians they trust, and they should be candid about these aspects of their history. These premises should be supported by advocates for gay and bisexual persons and substance abusers.

How could routine recommendation of HIV testing affect interaction between patient and physician? We believe it would provide a focus for and enhance efficiency of taking a history of risk for HIV. It would act as a probe to make the history more accurate — a good outcome if our earlier premises are correct. The interaction would begin with the physician saying in effect, "I recommend an HIV test to all my patients because some people who have risked exposure to HIV don't realize it, and many persons whose activities put them at risk find it difficult to disclose them." A brief risk history would follow.

The patients' responses would fall into three groups. The largest group would deny any risk history and would not object to being tested. Brief counseling would be given before the test. Those with absolutely no risk history would make a small financial sacrifice on behalf of those who are infected with HIV. Among those who have a risk history but deny it would be most of the people infected with HIV who would benefit from expanded testing.

A second group of patients would acknowledge risk histories. Of these, some would have done so whether a test had been recommended or not. In others, the reluctance to be tested can be used to elicit a more accurate history. All these patients should receive lengthy counseling. Some will and some will not permit testing. For those tested and found to be seronegative, counseling after the test must include information about the possibility of false negative tests.

The smallest group of patients would decline an HIV test without acknowledging activities putting them at risk. The physician's judgment would dictate the appropriate level of counseling. If broader HIV testing becomes the norm, the presence of a negative test in a patient's medical record will no longer be suggestive of a risk history for HIV. Those who refuse testing are more likely to be infected with HIV.[49] Whether they acknowledge a risk history or not, they should be encouraged strongly to seek public health facilities that offer anonymous testing.

We believe it no longer tenable to do less than strongly recommend an HIV test to all patients who acknowledge any sexual contact with homosexual men, any needle sharing, or multiple unsafe heterosexual contacts. Physicians should vigorously elicit such histories. Testing should also be recommended to those who received unscreened blood transfusions after 1977 (many of whom are unaware that they received them),[50] those with a history of any sexually transmitted disease (including acute hepatitis B), and those with lymphopenia, unexplained elevation of hepatic enzymes, or positive status for hepatitis B markers. Testing should also be encouraged for those who have been exposed sexually to any person who has tested positive for HIV or any untested person in the above categories.

We also strongly favor universal prenatal testing for HIV. The American Academy of Pediatrics and the American College of Obstetricians and Gynecologists currently recommend counseling and HIV testing of pregnant women who are "at increased risk of HIV infection."[51,52] This selectivity is inconsistent with the U.S. and Canadian decision to extend hepatitis B testing to all pregnant women because risk histories are often inaccurate.[53,54] Comparison with universal prenatal screening for rubella, which has been advocated since 1984,[55] is instructive. In the five years since 1984, there have been 21 cases of congenital rubella in the nation.[56] Since thousands of babies infected with HIV are born annually,[57] universal prenatal screening will prevent many more than five cases of neonatal HIV infection a year through decisions to have abortions or to limit the number of future pregnancies. If routine screening of pregnant women is accepted nationwide, its extension to the general population is logically only a small step.

Is it economical to recommend HIV testing to all adults who enter the health care system? Elderly women with negative risk histories are extremely unlikely to be infected with HIV. Perhaps our recommendation should be abridged to include only adults under 60 or in some parts of the country only men under 60. The problem of course is that if testing is justifiable in any segment of an apparently uninvolved population, the boundary between that segment and the rest of the population will inevitably be arbitrary. We urge serious consideration of recommending the test to populations with no apparent risk histories for HIV, especially if the prevalence of infection exceeds some very low threshold. We are recommending HIV testing vigorously to all U.S. adults under the age of 60 regardless of their reported risk history.

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DEPARTMENT OF VETERANS AFFAIRS

Patient Health Education: Prevention of HIV Infection/AIDS

Legal and Ethical Issues Related to HIV Infection
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May 17, 1989

I. Ethical responsibilities of health care providers

A. Doing good for the patient
B. Nonmaleficence -- "Physician, do no harm"
C. Self-determination for the patient -- all competent adults have the right to determine what shall be done to their own body

II. Practices which follow from these principles

A. Informed Consent -- patient may not be subjected to medical treatment without consent. Requires balanced and accurate presentation of benefits and risks(reasonable persons rule); includes right to refuse consent. Exceptions: emergencies when patient is incapable of consent. Query: What if physician reasonably believes that the patient's reaction to the information will pose a threat to the patient's health?

B. Confidentiality -- Concept has roots in Hippocratic oath ("Whatsoever I shall see or hear * * * I will not disclose, holding such things to be holy secrets).Based on right to privacy and self-determination, as well as fact that therapeutic relationship depends on trust. Privileges are legally protected in every state and physicians have been required to pay damages for breaching confidences. Exceptions: right to know(state reporting statutes); need to know (civil commitment statutes); risk to others (duty/right to inform third parties). Patients should know in advance what exceptions apply.

III. Is HIV infection a special case with respect to informed consent and confidentiality?

A. Other infectious diseases

B. Other sexually transmitted diseases

C. What makes HIV different? new disease, lack of understanding and information, fatal, discrimination

D. Public health considerations -- require confidentiality so people will be tested, counselled. Findings of Presidential Commission on HIV Epidemic.

IV. V.A. Circular 1-88-151 -- Testing for HIV and Informed Consent

A. General Policy -- VA will not conduct widespread testing for HIV unless specific funding to do so has been appropriated. All testing will be voluntary; all testing requires written informed consent and will be accompanied by pre- and post-test counselling. Persons recommended for testing: receiving treatment for IV drug use; receiving treatment for disease associated with HIV; at high risk for infection with HIV; upon request unless medically contraindicated.

B. Written informed consent form -- includes meaning of the test and of test results; transmission of HIV;confidentiality of test; possibility of discrimination;voluntary consent

C. Pre-test counselling --

1. The meaning, sensitivity and specificity of HIV test

2. Potential social ramifications of positive test result

3. Policies and guidelines for confidentiality of test result

4. VA policy on non-discrimination in health care services for HIV+ patients

5. Policy and guidelines on disclosure to public health authorities

6. Policy on disclosure to spouse or sexual partner

7. Measures to be taken for prevention of HIV transmission

8. Information relative to authorized disclosures

D. Post-test counselling -- include counselling for negatives

E. Document pre- and post-test counselling process in medical chart, including patient's mental status and comprehension

V. VA Policy on Confidentiality of Medical Records of Patients Infected with HIV -- Circular 10-88-134

A. Background -- VA policy is that all patient medical records are confidential. In addition, special protection has been afforded to records relating to drug abuse, alcohol abuse, and sickle cell anemia,because of sensitive nature of such information. Info from a medical record that would identify patient as being treated for one of these conditions disclosable only with written consent. VA has now added HIV to these conditions afforded special protection.

B. Exceptions to rule that no disclosure without consent:

1. May disclose to federal, state or local public health authority pursuant to law

2. In the case of a federal court order,disclosure is required. If order by a state court, the VA is not required to comply, but may use its discretion to do so

3. May disclose to medical personnel to extent necessary to meet a "bona fide medical emergency." "Medical emergency" is not defined -- query what is meant?

4. May disclose to qualified personnel for scientific research, management audits or program evaluations 5.May disclose to next of kin or personal representative of deceased patient if needed to obtain survivor's benefits

5. May disclose to next of kin or personal representative of deceased patient if needed to obtain survivors's benefits

6. May disclose to spouse or identified sexual partner under following conditions:

a. physician or professional counselor has made reasonable effort to counsel and encourage patient to tell

b. physician or professional counselor reasonably believes patient will not tell

c. disclosure is necessary to protect health of spouse or sexual partner

d. all of the above are documented in the patient's progress notes

C. Penalty for violating any provision of this circularis $5,000 for first offense and up to $20,000 for subsequent offenses. Possibility of lawsuit for private damages as well.

VI. Anti-discrimination laws

A. AIDS-specific statutes
Several local jurisdictions have specific ordinances prohibiting discrimination against individuals on basis of HIV status

B. State Handicap Law

Almost every state has legislation protecting people with physical and mental disabilities from discrimination. Slightly over half have extended this to include persons with AIDS or HIV. However, these state laws differ substantially in the types of discrimination they address: employment, public accommodation,credit transaction, education, health care

C. Federal Law

1. No AIDS specific law -- Rehabilitation Act of 1973, prohibits discrimination against"otherwise qualified" individuals with physical or mental disabilities.

2. Applies only to: program or activity receiving federal financial assistance, federal employees, federal contractors

3. Arline v. Board of Education -- Holds that a person with a contagious disease(there, tuberculosis), could be covered by section 504 of the Rehab Act. Not automatically covered -- must demonstrate that "otherwise qualified"

Test -- essentially must determine whether the individual would post a "significant risk" of infecting others, as indicated by medical evidence.

4. This concept was codified in the Civil Rights Restoration Act of 1988, which uses language that individual can't pose direct threat to health and safety of others.

5. Since Arline, federal courts have consistently applied section 504 to AIDS and later of HIV infection, and have consistently held in favor of plaintiffs, unless defendants could show rational, medical basis for discrimination.

Query: How does Rehabilitation Act apply to health care professionals and facilities?

D. Need for anti-discrimination legislation

1. Survey reported on in the New England Journal of Medicine, October 13, 1988

2. Persons known to be HIV+ face discriminatory attitudes and even outright hostility from a substantial number of Americans

3. 81% believe that in order to control the spread of AIDS, identifying persons with infection should take priority over privacy concerns

4. 1 in 5 say AIDS is a deserved punishment and those who are diagnosed are getting their rightful due

5. 29% believe HIV+ persons should be tattooed as to status -- this percentage doubled between 1985 and 1987

6. 1 in 4 said they would refuse to work with an HIV+ person

7. 1 in 4 said an employer should be able to fire an employee with AIDS

8. 32% of parents believe they should be able to keep their child out of a school that has a child with AIDS enrolled. This is up from 26% in 1985

Adapted in part from "Legal and Ethical Issues Related to HIV Infection/AIDS" by Jay A. Jacobson, M.D.

TREATING AIDS PATIENTS: CLINICAL, LEGAL, AND ETHICAL ISSUES

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A diagnosis of AIDS not only has medical implications for the patient; it will also affect family, friends, and colleagues. Everybody involved with the individual who tests positive for the antibody—who may be a practitioner or a patient—must contend with a unique set of medical, moral, and legal considerations to avoid discrimination against such a person.

The diagnosis of acquired immune deficiency syndrome (AIDS) is a significant stressor to the patient who receives this news, as well as to sexual partners and family members who must accept the clinical complexities and the stigma associated with the disease. Recent clinical research efforts address the ramifications of such a diagnosis and the associated stress.[1-7] This article explores a specified series of stages that patients with AIDS often experience during the course of their diagnosis and treatment, including related ethical and legal issues.

Recently, researchers have turned their attention to the ways in which stressful life events affect the immune system. Irwin et al. reported that changes in cell-mediated immune function have been noted in individuals undergoing stressful life experiences.[8] More specifically, lymphocyte responses to mitogen stimulation have been found to be lower in bereaved men and women two months after the death of a spouse than in age-matched control subjects. The investigators observed that individuals who experienced losses and distressing life changes demonstrated lower natural killer cell activity than those with few stressful life events.

AIDS ACCOMMODATION SYNDROME

Investigators had noted a series of crisis points that occur in the course of disease and illness that parallels Kübler-Ross' work with terminally ill cancer patients.[9-12] For AIDS patients, the major psychological stressor is the knowledge that they have contracted a terminal disease that could well result in a rapidly declining course of life.

Most patients who test positive for human immunodeficiency virus (HIV) suffer psychological trauma upon learning of their condition. Many such individuals will experience an "AIDS accommodation syndrome," which appears to involve a sequential processing of information on the part of the patient. Specifically, the syndrome addresses the accommodation process of the AIDS patient in adapting to the realization that he or she has a terminal illness. This syndrome usually includes the following psychological stages or phases in its recognition:

1. *Secrecy*, involving stigmatization, isolation, and self-blame.
2. *Helplessness*, with the realization that HIV-infection frequently causes a debilitating, terminal condition.
3. *Avoidance*, a stage of conscious or unconscious denial that relieves the patient from the trauma and confusion associated with such a diagnosis.
4. *Accommodation*, acknowledged by accepting the diagnosis and seeking medical care.

The stigmatization often attached to AIDS patients can give rise to a variety of legal dilemmas to which the legal specialist and health care provider must be attentive. When a society recognizes a wrong by way of judicial or legislative corrective measures, duties are created. Breach of duty may result in injury and, if such breach directly causes harm, in liability. A health care provider has a responsibility to provide sound medical care to an individual who has been accepted as a patient. Any deviation from the proper standard of care that results in injury may lead to liability on the part of the health care professional.

DUTY TO INFORM

The health care provider has a legal obligation to inform a patient who tests positive for the AIDS antibody of the known risks of this condition; failure to do so constitutes a deviation from the proper standard of care. The health care provider may also need to counsel the patient and/or the patient's contacts, who may also be at risk for contracting AIDS.

The VA has suggested that HIV testing be voluntary and based on clinical indications such as known or suspected exposure or clinical symptoms; that counseling be an integral part of any testing program, occurring prior to the test and again at the time the results are given; that patients understand their medical records will contain the test results—the VA is not an anonymous test site, although many communities have services or test sites where patients can be referred; and that consent forms neither be required nor recommended (however, if used as a local option, they are legal documents and should be reviewed for their lucidity, medical content, and legal implications).

A balancing of the interests of those involved may need to be considered when the AIDS patient's right to privacy is weighed against the compelling state interest to protect noninfected citizens from the disease. State and local mandatory reporting requirements vary greatly. Colorado has developed an effective program of identifying and educating the HIV-positive patient, which prescribes to the theory that counseling services for sex partners is in the best interest of all parties involved. Voluntary participation in such a program is certainly a prerequisite for its success.

Although AIDS patients usually insist on strict confidentiality, health care providers may share significant information with attending medical personnel or federal or state public health agencies. Such reporting should comply with acceptable standards of confidentiality. The federal penalty for improper disclosure under federal confidentiality laws is a criminal fine of $500 for the first offense and $5,000 for each violation thereafter.

AIDS patients should be informed of their obligations to warn their sexual partners

Similarly, AIDS patients should be informed of their obligations to warn their sexual partners and others who may run the risk of infection. Even HIV-infected individuals who may be little concerned about protecting others or avoiding liability should always be counseled thoroughly. The education process may encourage self-reporting and protection of the rights of others.

DUTY OF GOOD CARE

Patients with AIDS or AIDS-related illnesses should have the same access to treatment as does any other individual seeking health care. Federally funded programs for drug abuse treatment are prohibited from discriminating against AIDS patients who may be eligible for such therapy. The same laws apply to qualified handicapped individuals seeking employment, education, treatment, or other benefits or services.

All states require hospitals with emergency or trauma units to treat indigent patients at least to the point of stabilization prior to transfer to an indigent-care or community hospital. AIDS patients also must receive acceptable standards of care and treatment. Residential care programs offer the most exposure to liability for improper patient management. To limit liability, health care providers should establish policies for managing AIDS patients. Acceptable practices generally can be devised by following the guidelines of the American Hospital Association or the Centers for Disease Control, which stress appropriate medical precautions and confidentiality.

CONFIDENTIALITY AND INFORMED CONSENT

The general policy of the VA regarding informed consent provides that:

1. The practitioner must inform the patient of the name, nature, and details of the proposed diagnostic/therapeutic procedure or course of treatment, as well as the indications for expected benefits, associated risks, complications, side effects, reasonable and available alternatives, and anticipated results if no action is taken.
2. The practitioner with the primary responsibility for the patient or the one performing the procedure is responsible for providing the relevant information and obtaining consent.
3. The patient must have sufficient understanding and legal capacity to comprehend the information and communicate rational decisions regarding his or her medical care.
4. The patient has the right to know specifically who will be performing the procedure.
5. The patient must be advised if the procedure is novel, unorthodox, or educational, and must be made aware that

continued

refusal to undergo such a procedure will not jeopardize rights to receive standard or customary care.

The medical record should document the fact that the patient has been counseled appropriately, and the patient's informed consent should reflect that he or she has been apprised of the relevant aspects of the treatment as well as indications, risks, benefits, and alternatives.[13]

As stated, these regulations do not impose a legal duty on the VA to disclose to its patients whether health care professionals performing procedures or providing courses of treatment test positive for the AIDS antibody. Individual facilities may wish to adopt a policy—balanced in ethical considerations—to notify patients of facts that are material to their medical decision-making. However, such a policy must protect confidential employee personnel data against unnecessary disclosure.

The Centers for Disease Control do not summarily restrict ill health care providers from performing invasive procedures. Their guidelines do state that all personnel with evidence of any illness that may compromise their ability to adequately and safely perform invasive procedures, should be evaluated medically to determine whether they are physically and mentally competent. Furthermore, the Centers for Disease Control recommend that HIV-infected health care professionals, regardless of whether or not they perform invasive procedures, wear gloves to avoid direct contact with mucous membranes or non-intact skin of all patients, and those health care professionals with exudative lesions or weeping dermatitis should refrain from all direct patient care and from handling medical equipment until the condition resolves.

Under the present circumstances in which institutions have not established specific policies concerning medical care rendered by HIV-infected staff members, the case of Kapuschinsby v. United States, 248 F. Supp. 732 (D.S.C. 1966) may offer some guidance. In this case, a Navy hospital was found to be negligent in failing to prevent the transmission of a bacterial infection from a Navy corpsman to a prematurely born infant. The court determined that the hospital failed to act reasonably, breaching its duty to the plaintiff, by permitting an inexperienced corpsman to come in contact with the infant without first undergoing a complete physical examination that would have identified an infectious disease present in the corpsman.

The diagnosis of AIDS affects the patient's social support system

In a situation involving HIV-infected medical staff, a court would seek to determine whether the hospital acted reasonably and prudently under the circumstances. Any steps the hospital has taken to minimize or reduce the risk of HIV transmission would be significant in demonstrating reasonable and prudent action. In the absence of specific policies regarding medical staff members known to be HIV-infected, a lawsuit against the institution for its alleged failure to act reasonably and prudently in preventing HIV transmission would be subject to provisions of the Federal Tort Claims Act and may offer the employee immunity from personal liability.

When adopting a policy for preventing HIV transmission from staff to patients, the medical facility must balance its concerns for the health of its patients with the rights of its employees. A VA medical center must be careful not to discriminate against its HIV-positive health care professionals by excluding them from meaningful professional duties, including direct patient care. An employer of such a "handicapped" person cannot discharge that employee because of contagiousness, especially if that decision would be based solely upon the unsupported fears that others may become infected. The employer must accommodate reasonably the otherwise qualified employee while still taking into account the health risk that individual poses to others. An individual with a contagious disease who poses a significant risk of infecting others in the workplace will not be protected by federal laws if reasonable accommodation cannot eliminate that possibility.

All states have handicap discrimination laws, and two thirds have indicated a willingness to accept AIDS-related employment discrimination complaints or have determined such discrimination improper under their statutes. Some jurisdictions have taken steps to protect HIV-positive individuals from discrimination by making it illegal for health care professionals to test for the AIDS antibody or to release those results without the patient's consent. These laws are intended to help employers and others realize that a positive test does not necessarily mean a person will develop AIDS.

SUMMARY

As with other terminal illnesses, the diagnosis of AIDS affects the patient's social support system. It is this group of relatives, friends, colleagues, caregivers, and others that, along with the HIV-infected individual, experiences the trauma of awareness, recognition, and acceptance.[14-18] AIDS appears to generate a unique series of stages that allow accommodation and acceptance of this disease. Because the process of accommodation of this condition involves clinical, ethical, and legal considerations, health care professionals must be sensitive to the complexity of diagnosis and service provisions for the patient with AIDS.

continued

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Ethics

Edmund D. Pellegrino, MD

Two topics will be treated in this review—acquired immunodeficiency syndrome (AIDS) and surrogate motherhood. Each is chosen because it poses a wide variety of fundamental ethical dilemmas and illustrates the formidable obstacles that stand in the way of ethical consensus in our morally pluralistic society.

Without a vaccine or effective cure, primary prevention is mandatory if the world is to avoid a pandemic of human immunodeficiency virus (HIV) infections.[1,2] But the methods of prevention—change in sexual behavior, screening, and isolation—give rise to serious, unresolved ethical conflicts.

Behavioral change has been approached in two ways. One way emphasizes moral education aimed at achieving sexual abstinence or sexual monogamy; the other emphasizes explicit sex education, widespread use of condoms and their distribution in schools and colleges, and abortion for seropositive mothers. For many, the first method is unrealistic; for others, the second method sanctions and even encourages morally repugnant sexual practices. Reconciliation between these opposing moral viewpoints is essential to effective prevention but, at the moment, seems highly problematic.

Equally intensive disagreement surrounds mandatory screening, demands for which are rising in the general public (*Newsweek*, Feb 16, 1987, p 22).[3] The central ethical question is whether the risk is grave enough to justify the invasions of privacy and liberty that screening entails. The facts would seem to militate against such invasion. The epidemiologic data needed to answer this ethical question depend on screening, which itself poses numerous ethical and other problems,[4,5] such as cost, feasibility, loss of confidentiality, and fears of discrimination in jobs, housing, schooling, or insurance. Most difficult are questions surrounding the disposition of test results. Should positive reactors, their families, or sexual partners be informed? In addition, the right to know does not equal a desire to know. Yet, without knowing who is seropositive, it is impossible to protect sexual partners, prevent perinatal and intrauterine infection, or avoid transmission via infected blood

The present hope is that voluntary screening and modification of sexual practices will suffice. But there have already been instances of seropositive individuals who persist in sexual promiscuity and who may even do so deliberately to retaliate for their own infection. Should they be identified and coerced into compliance or forcibly isolated?[4]

There is disagreement about who should undergo screening. It seems that some selected samples of the high-risk and general populations need to be screened to fill in the epidemiologic gaps and create the basis for rational public health policies. Mandatory screening already exists in the military. Should other subgroups—eg, prisoners, prostitutes, drug addicts, immigrants, patients admitted to hospitals, pregnant women, those privy to state secrets, or those seeking marriage licenses—be included?[6,7] An unexplored reservoir of infection may exist in the large number of people who received blood transfusions before donor screening became routine.[8] Should they, their families, and their sexual partners be screened and informed? At the moment, the drawbacks—counterproductivity and the invasion of human rights—outweigh the benefits of mandatory screening,[4] but new facts may change this situation at any moment.

Intensive disagreement surrounds mandatory screening for AIDS

Nonsexual intimate contact seems to pose little risk, even for health workers,[9,10] although in June 1987 the Centers for Disease Control reported three cases of AIDS from occupational exposure to blood products (*Newsweek*, June 1, 1987, p 55). Should patients and surgeons be screened before operations? Should HIV-positive surgeons be prevented from operating or their patients informed?

When a physician is confronted with an HIV-positive patient, issues of confidentiality arise. Does the physician's duty of confidentiality override his or her duty to protect a positive reactor's family? Should the identity of positive reactors be reported, as now required in a few states? Are physicians justified in underreporting AIDS as a cause of death to protect privacy or the feelings of the family?[11]

Equally vexing questions cluster around the care of patients with AIDS. Do the discouraging results, fears of contagion, considerable costs, or needs of other patients influence the physician's decision to treat? Patients with AIDS often suffer dementia, depression, and memory loss, making valid consent to treatment, experimental therapy, or do-not-resuscitate orders morally problematic. Yet, anticipatory consent while patients are still competent could undermine confidence and destroy hope.[12]

As we discover potentially effective therapeutic agents, like zidovudine or peptide-T, other ethical issues will arise, ie, those of controlled trials, experimentation on fatally ill patients, and early treatment before the appearance of clinical symptoms.[13] Beneficence dictates that every therapeutic possibility be made available expeditiously. But clinical experience repeatedly teaches the long-term harm of uncontrolled therapeutic trials. This is a particularly painful dilemma and one that is difficult to explain to the public and to patients with AIDS.

An especially prickly problem is whether physicians can ethically refuse to care for patients with AIDS.[14-17] Here the history of medical ethics is unclear. Distinguished physicians have fled the plagues of the past, others have stayed, often to die. The American Medical Association's code of 1847[18] imposes on physicians the responsibility to "face the danger" even "at the jeopardy of their own lives." Some physicians today debate this point on the grounds that physicians may choose whom to treat, a right guaranteed by the present American Medical Association principles, or by contending that AIDS had not been heard of when they entered medical school and so its treatment is not in their "contract" with society.[9,10] Resolution of this conflict is an urgent obligation of the whole profession if its moral integrity is to be preserved.

Another set of complicated ethical issues is inherent in the use of the newer reproductive technologies. Genetic, gestational, and nurturing parenting can now be separated or combined in a bewildering array of possibilities by various combinations of artificial insemination, in vitro fertilization, and embryo transfer or freezing.[19] The distressing complications of surrogacy were publicly exposed in the litigation between the Whitehead and Stern families over custody of "Baby M," when Mrs Whitehead defaulted on her "contract" to hand over the child conceived with Mr Stern's sperm. Even the most pragmatic ethicist must pause before the difficulties this case presents.

Thus far, the courts have concentrated on questions of contract and custody, ignoring the ethical issues involved in the commercialization of baby production.[20-22] Is there any limit to what one person may pay another to do? Is surrogacy an "alternative reproductive vehicle," as Judge Harvey Sorkow called it?[22(p17)] Do surrogate arrangements dehumanize reproduction by making women into "baby factories," exploiting poor women, and violating the biologic bond forged by gestation? Does surrogacy impose unacceptable emotional burdens on the contracting parties and on the child? Are infertility and inconvenience sufficient warrant for renting another's womb? Can a third party reap monetary benefits from such a contract? Does it make a difference if the surrogate volunteers, refuses a fee, or is single? Who will care for a handicapped child? Can abortion be built into the contract if the "product" is less than perfect?

Are infertility and inconvenience sufficient warrant for renting another's womb?

The answers to such questions touch on the most fundamental and divisive philosophical, religious, and political values. What is at issue is whether some things ought never be done, whether morality is a totally private affair or a matter for social sanction, and the extent to which law should intervene in reproductive morality.

The legal, ethical, and religious debates will be sharpened by the opposing opinions, published this year, of two influential bodies. The American Fertility Society[19] finds most forms of reproductive technology acceptable. It also permits freezing and experimentation with embryos aged less than 14 days, calling them "pre-embryos." The Vatican Instruction,[23] on the other hand, while recognizing the importance of continuing research in reproductive technology, finds artificial insemination, in vitro fertilization, and embryo freezing and experimentation morally repugnant. It rejects the concept of pre-embryos and the permissibility of embryo experimentation and reasserts the obligation to protect life from the time of conception.

The ethical issues raised by AIDS and reproductive technology are emotionally and conceptually charged. They challenge our deepest belief systems. Public good must be balanced against individual good and technological advances subjected to moral constraint. Ethicists, physicians, and policymakers are under an obligation to lead society in careful and judicious deliberation of these pertinent issues.

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21. *Smith & Smith v Jones & Jones*, Detroit 3d Sub Dist (No. 85.532014 D2, March 1986).
22. *In re Baby "M,"* NJ Super Ct Ch Div/Family Part, Bergen County (No. FM-25314-86E, March 31, 1987).
23. *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day*. Vatican City, Confederation for the Doctrine of the Faith, 1987.

Government

Wayne Bradley

The challenge to government and medicine that has been in process for more than a decade intensified during the past year. The challenge is to maintain access to and quality of care while containing costs.

Medicare and Medicaid were enacted to offer medical assistance to the elderly and needy without interfering with the private practice of medicine. The intention was to provide the benefits of private care to all citizens regardless of whether reimbursement was through private or public funds. Shortly after the programs began, their costs exceeded projections, and the government immediately began searching for ways to contain public-care costs while maintaining private-care quality.

Following that model, the second session of the 99th Congress closed last year with legislation that set Maximum Allowable Actual Charges for physicians who serve Medicare patients but who did not sign "participating" agreements to accept the program's assignment of fees. The legislation widened the difference in reimbursement to participating and nonparticipating physicians and also cut fees to ophthalmologists by 10% and placed a cap on charges for cataract extractions. At the same time, Congress ended a long-standing fee freeze levied against physicians offering Medicare services, killed the already moribund Health Planning Act, and provided legal immunity for physicians participating in good faith peer review, with the caveat of a clearinghouse to track all disciplined health care providers.

In the 100th Congress, Democrats gained control of both houses of Congress for the first time in six years. They set a target of $1.5 billion savings in Medicare, with $1.1 billion to come from hospital payments and $400 million from physician services. Those savings would be realized from limited updates in the Medicare economic index. Additional savings would come from fee cuts for certain procedures under the inherent reasonable authority.

The American Medical Association (AMA) has backed concurrent resolutions introduced in both houses of Congress opposing a diagnosis related group prospective pricing system for physicians and mandatory assignment of physician reim-

VETERANS ADMINISTRATION
Department of Medicine and Surgery

Confidentiality Concerns

Purpose: The purpose of this paper is to outline some of the deep concerns related to confidentiality that trouble many VA employees dealing with AIDS patients and patients with HIV infection and to suggest a task force to review policies and practice. This is a recurring theme in much of the writing about AIDS and yet assurances have been given that existing laws cover the sensitive information about AIDS just as they cover other medical information. The reasons for the continuing concern and some possible solutions in the VA are examined.

Discussion: Confidentiality of information obtained through the doctor-patient relationship has a long history of recognition and respect which has generally been extended to medical information obtained in the course of medical treatment. Current rules were developed before the AIDS epidemic began. We need to explore the limits of current law and policy to see if modifications to current rules are needed to accommodate the special circumstances created by the AIDS epidemic. Concerns fall in four general categories:

> The Medical Record - Information in the medical record is protected by law from unauthorized disclosure. However, it is often unclear whether the patient understands what information is actually included in his/her medical record when release is authorized.
>
> Information that "floats" around a hospital's grapevine - Many people have access to the chart or the information in it who may have a need to know the medical information (physicians, nurses, respiratory therapists, dentists, etc.) and others who do not (housekeeping staff, laboratory technicians, dietetics workers, ward clerks, etc.) Hospital staff have many opportunities to share this information in the community with or without malicious intent.
>
> Information that is maintained outside the chart - There are indications that some medical centers maintain lists of patients with AIDS or HIV infection in logs and computers in laboratories, clinics and various offices which could be misused were they to fall into the wrong hands. The appropriateness of such practices and methods for protecting this information need review.
>
> Appropriate disclosure of AIDS information - It is generally agreed that a clearly stated written policy on appropriate disclosure of AIDS information to agencies and individuals is needed.

Why is this information related to AIDS different from information about tuberculosis or alcohol and drug abuse or psychiatric illness? The answers seem self-evident when the media covers stories of people with AIDS being fired or evicted from apartments, homes of children with HIV infection who want to go to school being burned to the ground and respected surgeons announcing that they would refuse to operate on people with HIV infection. The stigma of being infected with "the AIDS virus" is great because the level of fear of infection in many communities is overwhelming. While the medical community is aware of the data which argues compellingly against casual spread and insect vectors, the lay public is deluged with "information" issued by putative "experts" and they are often unable to distinguish between fact and fiction. They cannot distinguish between various routes of spread of infectious agents and only remember that swimming pools were implicated in the spread of polio (an enteric virus spread by the oral fecal route) and that isolation of patient was used to control tuberculosis (a mycobacteria spread by the respiratory or airborne route) and smallpox (a virus spread by direct contact with skin lesions and respiratory discharges.) However, the one characteristic of AIDS that everyone understands is that in its full blown or most dramatic manifestation, it is invariably fatal. This colors the thinking of most people and leads to the fear that influences and justifies behaviors that hark back to a less enlightened age. Another factor that influences attitudes is the occurrence in the United States of the syndrome primarily in certain groups of people, homosexual or bisexual males and IV drug abusers, who are stigmatized by many in the mainstream of American society.

AIDS has been labeled the single public health challenge in the second half of the twentieth century. This has led to an understandable need to "do something" on many levels and the availability of an inexpensive screening test has offered that "something." Introduced as a way of screening the blood supply, a significant route of spread, it was an easy step to view it as a way of identifying individuals who were infected with the virus and therefore both at risk of developing the disease, AIDS, and of infecting others. Screening linked with counselling to reduce spread is currently recommended by the Public Health Service and is becoming routine practice in some settings. As the number of Americans who have been tested increases, the need for confidentiality has increased because of the reported incidents where disclosure of a positive test status has had devastating consequences for the individuals involved. At the same time, persons who feel that they have a need to know this information because of their role in determining therapies for individuals or public policy related to the disease or because of their unavoidable exposure to blood and body fluids have become more vocal in expressing their concerns that undue or excessive protection of confidentiality may be counterproductive to both individuals and society at large. VA should have a single standard of confidentiality throughout the country. In that connection, we should emphasize the importance of VA employees being aware of their responsibilities in assuring patient confidentiality and of the relationship between federal law and various state laws on this subject. This can be a particular problem for part-time employees who work in both VA hospitals and state or private facilities.

In summary, the problem for the VA is not unlike the problem the entire health care community faces:

> How can the patient's right to confidentiality be preserved thus encouraging those who may be infected to seek necessary care without fear of discrimination while at the same time allowing for certain routine disclosures, such as those to public health authorities and other caregivers who will participate in the health care the patient needs? And how can compliance by employees with the policies that apply to AIDS be assured?

Recommendations: It is quite possible that there will be some legislative action related to confidentiality with the number of bills pending at the present time. However, regardless of what happens on the legislative front, there seems to be a need for the Veterans Administration to take some positive steps to review and, if necessary, clarify current policy and make sure that all employees are familiar with the relevant regulations and laws. Therefore, it is recommended that a Task Force be set up to study existing federal laws and regulations and to (1) recommend regulatory or policy change as appropriate and (2) to develop ways to assure that existing laws and regulations are understood by VA employees in the field. The scope of the Task Force's activities could be expanded to include identification of recommended legislative initiatives, however, the more immediate concern is to tailor policy under current statutory authority to meet the needs generated by the AIDS epidemic. The Task Force should be composed of representatives from the AIDS Working Group, the General Counsel, Operations and/or the Medical Regions, Clinical Affairs, Medical Administration, and Legislative Affairs. The need for field input could be handled by a representative from the field or a member of the AIDS Steering Committee.

Susan H. Mather, MD, MPH Chairman, AIDS Working Group (10A7)10/13/87

AIDS
PROGRAM OFFICE
VETERANS
ADMINISTRATION

AIDS GRAM

"Success starts with my actions today."

VACO AIDS Program Office

Newsletter for AIDS Coordinators
MAY, 1988

Director's Corner

S. Mather

Public Law 100-322 was signed by the President on May 20, 1988. As I discussed last month when this legislation was known as H.R. 2616, this will change the way we do business related to AIDS in a rather dramatic fashion. The two areas that will have the greatest effect are in confidentiality and informed consent for HIV testing. While information about HIV status is given new protection under the law, the VA will now have the authority to release information about HIV status to spouses and sexual partners. The information can only be disclosed by a physician or professional counselor after "reasonable" attempts to get the patient to voluntarily reveal the information have failed. A circular and information letter will be forthcoming on the subject in the near future. Written informed consent will now be required for all HIV testing. A VA Informed Consent for HIV Testing form is being developed. In the meantime, local forms can be used to document patient consent or the patient can sign an applicable statement in the progress notes. You will be receiving more information on the implementation of P.L. 100-322 through conference calls, circulars and information letters. Much of our time and energy in the AIDS Program Office will be devoted to this in the next several months.

Dr. Allen, Deputy Director, AIDS Program Office, will be going to Stockholm to the IV International AIDS Conference in June to present a paper entitled, "AIDS in the Veterans Administration: Demography and Epidemiology" during two poster sessions. He will be summarizing the conference in next month's AIDS GRAM. We look forward to having the latest information on AIDS. The CMD Steering Committee on AIDS/HIV Infection will meet June 21-22, 1988. They have identified AIDS in the drug abusing population as a priority and will be discussing ways to reach this unique group.

In closing, I want to urge you to keep your submissions to the AIDS Patient Registry up-to-date. Only recently we had a Congressional inquiry on the "top 25" VA medical centers in terms of AIDS work load. Obviously, the cutoff is artificial. However, in the past, Congress has expressed a belief that special assistance needs to be provided to those VAMCs with the heaviest work load. In this instance, the chances are good that some increase in funding will directly reflect the information which was provided to Congress. Accurate and timely reporting is in everyone's best interest. I know you would not want your VAMC to miss out for lack of reporting. I will be attending at least one of the Train-the-Trainer Programs this summer and I look forward to seeing some of you then.

Pharmacy Service Report

J. Ogden

The Burroughs Wellcome Company reports that the VA purchased 20,109 bottles (100 capsules/bottle) of AZT at a cost of $3,323,271 during the period of September 1, 1987, to April 30, 1988. This figure extrapolates to an annual usage rate of 30,163 bottles at a cost of $4,531,689 to the VA (at the current GSA rate of $150.24/bottle).

On May 20, 1988, a one-day census of 226 VA Pharmacies was conducted with the following results: 1,039 patients were being treated with AZT and 10,969 capsules of AZT were being taken on that day.

Origin of AIDS

While the origin of the epidemic is still unknown, a number of articles have presented some interesting speculations. For example, like many of the previous epidemics it could have started in animals. If so, it is probably a virus that does not greatly affect them and only becomes a fatal epidemic in humans.

Another possibility is that AIDS could have been harbored by isolated peoples for many years before breaking out into an epidemic. In this scenario, a small group of people resistant to the effects of the virus have long had it and only recently passed it out to the world as civilization reached them. In any scenario, the virus must have mutated from a less harmful one to a fatal one and the virus must have broken out of an animal or human enclave to infect people around the world.

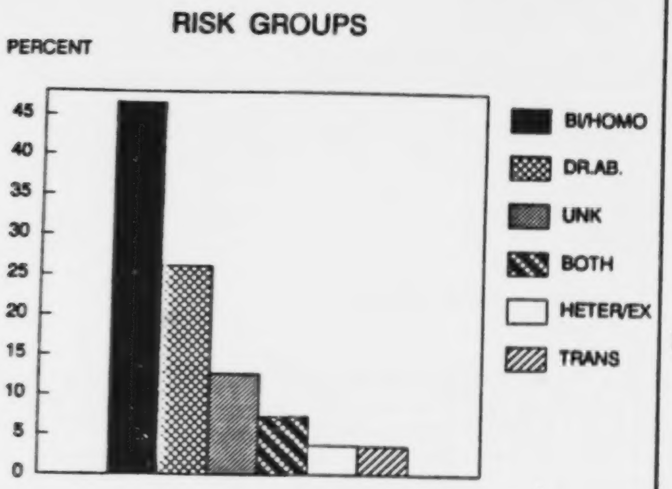
The green monkey hypothesis has been largely discredited. Molecular analysis shows that the virus infecting monkeys was probably not the ancestor of the AIDS virus. The origin of both viruses is still a mystery. Green monkeys live and are eaten in West Africa where there is little evidence of AIDS, not in Central Africa where AIDS is more prevalent.

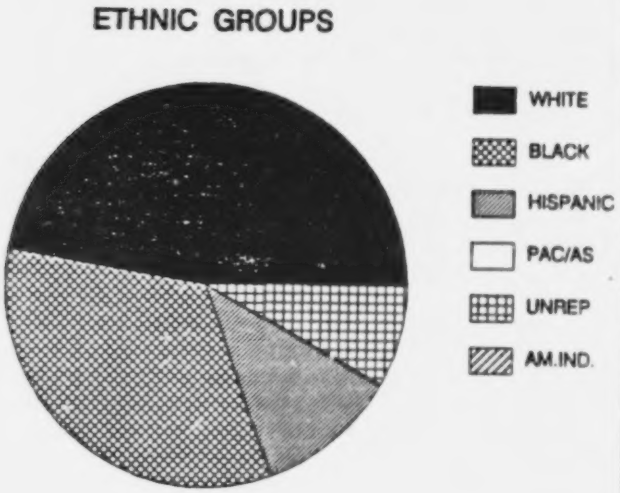
THOUGHT FOR THE DAY:

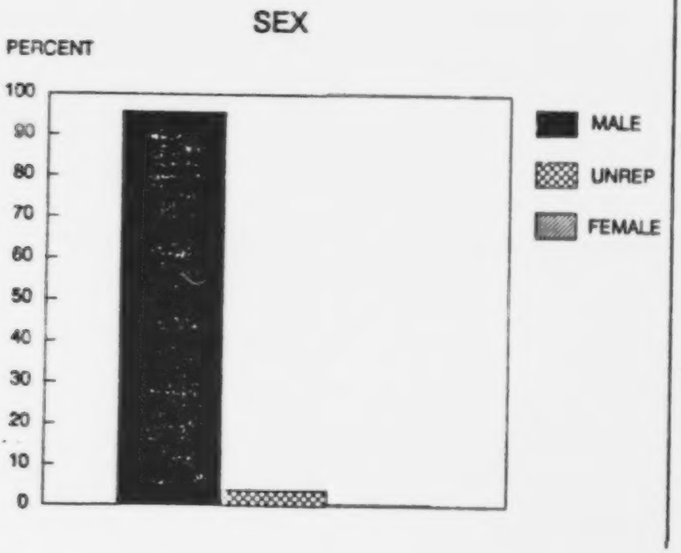
"In a calm sea every man is a pilot."

John Ray

CHANGE: Please change your April AIDS GRAM telephone listing for Lance George, M.D., Director of the AIDS Clinical Unit, West LA from FTS 794-4104 to FTS 794-6206.







AIDS PATIENT REGISTRY

Demographic Update

May 31 ,1988

Cumulative total	4313
New patients reported this month	181
Average new patients per month in 1988	168

RISK FACTOR:

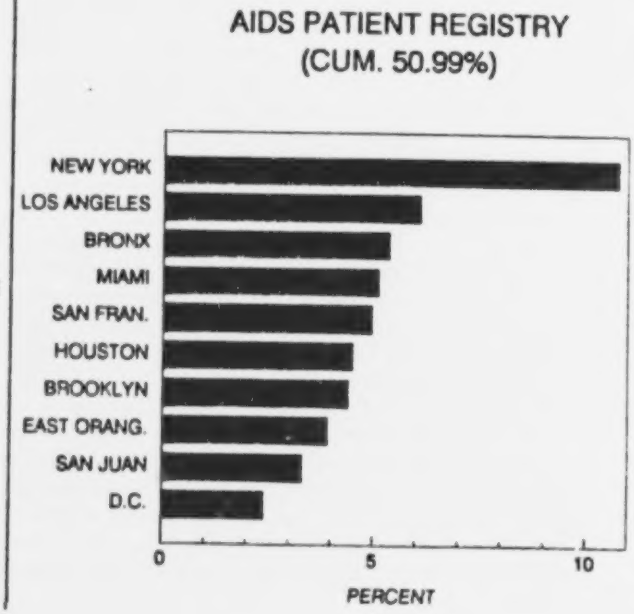
Homosexuals or Bisexuals	2011
IV Drug Abusers	1126
Both Homosexuals and IV Drug Abusers	315
Heterosexual contacts	158
Transfusion	155
Unknown or unreported	548

ETHNIC:

White	2045
Black	1425
Hispanic	487
Unreported	346
Pac/Asian	7
Am. Indian	3

SEX:

Male	4129
Unreported	168
Female	16



1. INTRODUCTION:
    - A) Introduce Yourself & Identify Your Role
    - B) Purpose Of Counseling Session
    - C) Introduce The Concept Of Informed Consent
2. ASSESSMENT:
    - A) Interest In Being Tested
    - B) Knowledge About The Test
    - C) Knowledge About Transmission Of HIV
    - D) Risk
3. INFORMATION ABOUT THE TEST:
    - A) What It Measures
    - B) What A Positive Test Means
    - C) What a Negative Test Means
    - D) Sensitivity & Specificity of Test
    - E) Repeat & Confirmatory Test for Positive Screening
    - F) Timing Of Test
    - G) Testing Procedure
4. TRANSMISSION OF HIV:
    - A) Blood
        - Transfusion
        - Needle-Sharing
    - B) Intimate Sexual Contact
    - C) Infected Mother to Infant

5. PREVENTION:

A) Blood

- Avoid Sharing Injection Equipment ("Works")
- Disinfection With Bleach

B) Sexual

- Abstinence
- Mutual Monogamy
- Avoid Persons At Increased Risk
- Users Of IV Drugs
- Male/Female Prostitutes
- Persons With Multiple Partners
- Limit The Number Of Sexual Partners
- Avoid Activities That Could Tear Linings of Vagina, Rectum, Penis
- Increased Risk With Receptive Anal Intercourse
- Condoms
- Spermicides

C) Exposed Women During Childbearing Years

- Postpone Pregnancy Till Infection Status Determined

D) Application To Patient's Lifestyle

- Patient's Perception of "Safe Sex"
- Changes To Reduce Exposure To HIV

6. VOLUNTARY NATURE OF TESTING:

7. CONFIDENTIAL TESTING:

   A) Confidentiality VS. Anonymity

   B) Recording Of Results In Chart

   C) Reporting To Public Health Authorities

   D) Policy On Disclosure To Spouse/Sexual Partner

   E) Procedure For Disclosure Of Test Results/Medical Records

   F) Anonymous Testing At Community Sites

8. IMPLICATIONS OF TEST RESULTS:

   A) What Will This Mean For The Patient If He Tests:

      - Positive

      - Negative

   B) Patient Expectations About Test Results

   C) Evaluation Of Patient's Coping Skills

   D) Evaluation Of Patient's Support System

   E) Possible Social Ramifications Of Test Results

   F) Health Care Services Available In VA For HIV(+) Patients.
   DECISION:

      - Does The Patient Have Enough Information To Make A Decision?

      - VA Form 10-0121 (Consent Form)

10. CLOSURE:

   A) Arrange F/U Appointment To Receive Results

   B) Results Delivered In Person Only

   C) Printed Educational Material

D) Stress Good Health Practices

11. DOCUMENTATION:

Counseling Process Documented In Progress Notes of Patient's Chart - PL-100-322

SOME COMMON ELEMENTS OF HEALTH BEHAVIOR CHANGE

Each of us has had a personal experience with behavior change from which we can draw lessons for prevention of HIV disease. As you recollect a recent experience with which you have had some success, list some aspects of this change in the space below.

1. What **prompted** you to consider making the change?

2. What was an **incentive** that helped you get started?

3. Name a **barrier** that stood in your way of accomplishing or continuing the change.

4. What helped your **overcome** the barrier and/or **reinforced** the change in your behavior?

Circle the item above which was the most important to you in your personal experience of behavior change.

As your fellow participants discuss the important aspects of their experiences, list some of them below.

Veterans Administration
Department of Medicine and Surgery
Washington, DC 20420

CIRCULAR 10-88-134

November 7, 1988

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Public Law 100-322, Section: 121 Confidentiality of Medical Records of Patients Infected with the Human Immunodeficiency Virus (HIV)

1. PURPOSE: The purpose of this DM&S Circular is to establish policy on maintaining the confidentiality of medical records that include information concerning an individual's tests for or infection with the Human Immunodeficiency Virus (HIV). This circular is a new issue and will be incorporated into M-1, part I, chapter 9.

2. POLICY:

a. Title 38 U.S.C. 4132, provided for the confidentiality of Veterans Administration medical records that were maintained in connection with the performance of any program or activity (including education, training, treatment, rehabilitation, or research) relating to drug abuse, alcoholism or alcohol abuse, or sickle cell anemia. Information from a medical record that would identify a patient as being treated for one of these conditions could have been disclosed only with the specific written consent of the individual or as permitted by one of the limited exceptions of 38 U.S.C. 4132(b)(2). VA Form 10-5345, Request for and Consent to Release of Drug Abuse, Alcoholism or Alcohol Abuse or Sickle Cell Anemia Information from Medical Records, includes the required elements for a specific consent and is used to obtain the patients' written consent for disclosure from these records.

b. Title 38 U.S.C. 4132 was amended by Pub. L. 100-322, the Veterans' Benefits and Services Act of 1988, which was signed by the President on May 20, 1988. In addition to other changes, Section 121 of Pub. L. 100-322 adds medical records of patients who are tested for or infected with the HIV to the confidentiality provisions of this section. VA Form 10-5345 is being revised to change the form title and to include records that contain information concerning an individual's test for or infection with the HIV. VA regulations are being written to include the confidentiality provisions of 38 U.S.C. 4132.

c. As amended, 38 U.S.C. 4132(b)(1) provides that the treating physician or a professional counselor may disclose information indicating that a patient is infected with the HIV if the disclosure is made (1) to the spouse of the patient, or (2) to an individual whom the patient has, during the process of professional counseling or of testing to determine whether the patient is infected with the virus, identified as being a sexual partner of the patient. This section of the law cannot be implemented until 30 days after Privacy Act routine use statement for the Patient Medical Records system of records (24VA136) is announced for public comment in the Federal Register. A separate circular will be published which will address DM&S policy on testing to determine whether patients are infected with the Human Immunodeficiency Virus and pre-test and post-test counseling.

d. In the case of a patient with a positive HIV test result who has a spouse, or who during HIV pre-test counseling identifies an individual as being a sexual partner, the treating physician or professional counselor will document in the progress notes of the medical record the factors that are considered which lead to a decision as to whether an unconsented disclosure of the HIV infection information should be made to the patient's spouse or sexual partner. Disclosures described in the preceding subparagraph c may be made only if the treating physician or counselor, after making reasonable efforts to counsel and encourage the patient to provide the information to the spouse or sexual partner, reasonably believes that the patient will not provide the information to the spouse or sexual partner and that the disclosure is necessary to protect the health of the spouse or sexual partner. Any disclosure to a spouse or sexual partner will be fully documented in the progress notes of the patient's medical record. As required by 38 CFR 1.576(c), an accounting will be kept of each such release of information. If the treating physician or counselor who counseled the patient about providing the information to the spouse or sexual partner is unavailable due to absence on extended leave or termination of employment, disclosure to the spouse or sexual partner may be made by another physician or counselor. Before any patient gives consent to being tested for the HIV, as part of pre-test counseling, the patient must be informed fully about these notification provisions. (NOTE: The legislative history indicates that where the treating physician or counselor is not available due to a brief absence, such as a short sick leave or vacation, the aforementioned disclosure should ordinarily still be made by the treating physician or counselor when that person returns.)

3. ACTION:

a. Veterans Administration patient medical records information concerning an individual's tests for or infection with the HIV are confidential. Records are confidential that pertain to the testing for infection with the HIV whether the test results are negative or positive for infection. Information from these records will be disclosed only with the specific written consent of the individual who is the subject of the medical record or as permitted by 38 U.S.C. 3301 and 4132, The Privacy Act of 1974 (5 U.S.C. @@552a), and this circular. Generally, the redisclosure of this informaton, disclosed under authority of a specific written consent, is prohibited without the patient's specific written consent. The person to whom such information is disclosed should be so advised.

b. Other than the patient who is the subject of the medical record, no person or entity may be advised that a special written consent (such as VA Form 10-5345) is required in order to disclose medical record information relating to drug abuse, alcoholism or alcohol abuse, tests for or infection with the HIV, or sickle cell anemia. As indicated, where a person presents the VA with an insufficient consent for records protected by 38 U.S.C. 4132, the VA must, in the process of obtaining a legally sufficient consent, correspond only with the patient whose records are involved and not with any other person.

c. Information relating to an individual's test for or infection with the HIV may be disclosed from a medical record to a Federal, State, or local public health authority that is charged under Federal or State law with the protection of the public health. A Federal law (or State law as to State facilities) must require disclosure of the information for a purpose that is authorized by law and a qualified official of the public health authority must make a written request for the information (38 U.S.C. 4132(b)(2)(C)). The disclosure of patient name and address under this provision must be permitted also by 38 U.S.C. 3301(f)(2) which provides for the disclosure of patient name and address "to any criminal or civil law enforcement governmental agency or instrumentality charged under applicable law with the protection of the public health" so long as such disclosure is for a purpose authorized by such law. Therefore, a public health authority may be provided with the name and address of a patient who is infected with the HIV only if such authority is charged with law enforcement responsibility in enforcing the reporting of such information. Such disclosures are permitted by the Privacy Act, 5 U.S.C. 552a(b)(3) (see 38 CFR 1.576(b)(3)), and routine use statement number 12 of the Patient Medical Records-VA (24VA136) Privacy Act system of records that is set forth in Appendix B, Chapter 21, MP-1, Part II, and amended in the Federal Register on July 17, 1986 (51 FR 25968), December 9, 1986 (51 FR 44406), and January 5, 1987 (52 FR 381). As required by 38 CFR 1.576(c), an accounting will be kept of each release of information processed under this paragraph. (NOTE: A routine use statement will be published for public comment in the Federal Register that will address specifically the disclosure to public health authorities of medical record information concerning an individual's infection with the HIV.)

d. The policy included in this circular and paragraph 9.62 of M-1, Part I, will be followed in the release of information to public health authorities. Information that is disclosed to public health authorities will be limited to that information which is required by law. In making a disclosure of HIV infection information to a public health authority, information may not be released regarding a patient's treatment for drug abuse, alcoholism or alcohol abuse, or sickle cell anemia. Information concerning an individual's use of needles for self-injection of drugs not prescribed by a physician may be reported to public health officials in the collection of data base information as a social and risk factor if the information is obtained in connection with a program or activity relating to testing for or infection with the HIV. However, such information cannot be reported if it is recorded for purpose of treatment for drug abuse. The person to whom information is disclosed will be notified in writing that the information may not be redisclosed or used for a purpose other than that for which the disclosure was made. The notification will inform the person of the penalty provisions that are included in subparagraph g of this paragraph. (NOTE: This disclosure provision does not provide for the release of information relating to an individual's infection with the HIV to Federal, State, or local authorities who are not charged with the protection of public health, but who are charged under Federal or State law with the protection of the public safety.)

e. Medical record information relating to drug abuse, alcoholism or alcohol abuse, testing for or infection with the HIV, or sickle cell anemia may be disclosed without patient consent under the following circumstances:

(1) To medical personnel to the extent necessary to meet a bona fide medical emergency.

(2) To qualified personnel for the purpose of conducting scientific research, management audits, or program evaluations. The person who receives the information may not identify, directly or indirectly, any individual patient in any research, audit or program evaluation report, or otherwise disclose patient identities in any manner.

(3) If authorized by an appropriate order of a court of competent jurisdiction (either Federal or State) which is granted after an application which shows good cause for disclosure. However, such an order from a State court only acts to authorize the VA to exercise discretion to disclose such records. The procedures set forth in 38 CFR 1.511(c), should be followed in the State court order situation. In assessing good cause, the court must weigh the public interest and the need for disclosure against the injury to the patient, to the physician-patient relationship, and to the treatment services. In the granting of such an order, in determining the extent to which any disclosure is necessary, the court should be encouraged to impose appropriate safeguards against the redisclosure of information which is required to be disclosed by the order. A subpoena does not constitute a court order for purposes of 38 U.S.C 4132(b)(2)(D).

f. The provisions of 38 U.S.C. 4132 and this circular apply to the records of any patient who is deceased. Information may be disclosed only upon the written request of the next of kin, executor, administrator, or other personal representative of the patient, and only if the Medical Center Director, or designee, determines that the disclosure is necessary for the survivor to obtain benefits.

g. Any person who violates any provision of 38 U.S.C. 4132 or this circular shall be fined up to $5,000 in the case of a first offense, and up to $20,000 in the case of a subsequent offense.

4. REFERENCES;

a. Sec. 121, Pub. L. 100-322, Veterans' Benefits and Services Act of 1988.

b. 38 U.S.C. 3301 and 4132.

c. 42 CFR 2.1 through 2.67.

d. 38 CFR 1.500 through 1.527 and 1.575 through 1.584.

e. The Privacy Actof 1974, 5 U.S.C. 552a.

f. DM&S Circular 10-88-49, Public Law 100-322, Section 124: HIV Testing Standards.

5. RECISSIONS: This DM&S circular will be rescinded on November 7, 1989.

6. FOLLOW-UP RESPONSIBILITY: Director, Medical Administration Service (136F).

/s/
JOHN A. GRONVALL, M.D.
Chief Medical Officer

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Veterans Administration
Department of Medicine and Surgery
Washington, DC 20420

CIRCULAR 10-88-151

December 14, 1988

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities; Domiciliary; Outpatient Clinics; and Regional Offices with Outpatient Clinics

SUBJ: Public Law 100-322, Section: 124 Testing for HIV (Human Immunodeficiency Virus) and Informed Consent

1. PURPOSE: This DM&S Circular establishes policy on the required elements of testing for the HIV (Human Immunodeficiency Virus) and references policy on maintaining the confidentiality of medical records of patients who are treated for the HIV or HIV-related disease. This circular is a new issue and will be incorporated into M-2, part I, chapter 23.

2. POLICY:

a. Public Law 100-322, the Veterans' Benefits and Services Act, was signed by the President on May 20, 1988. This law contains four sections which pertain to HIV:

(1) Section 121, Confidentiality of Medical Records,

(2) Section 122, Nondiscrimination,

(3) Section 123, Information and Training Concerning AIDS Prevention, and

(4) Section 124, Restriction on Testing for Infection with the Human Immunodeficiency Virus.

This circular establishes policy on provisions contained in Section 124, Restriction on Testing, and applicable aspects of other sections as they pertained to testing for HIV. VA policy derived from Section 121 pertaining to the confidentiality of medical records is established in Circular 10-88-134, "Public Law 100-322, Section 121, Confidentiality of Medical Records of Patients Infected with Human Immunodeficiency Virus." In summary, Pub. L. 100-322 added medical records of patients who are tested for or infected with HIV to the same confidentiality restrictions as those applied to any program or activity related to drug abuse, alcoholism or alcohol abuse, or sickle cell anemia, with certain exceptions for release of HIV information.

b. Section 124, Restriction of Testing, mandates prior written informed consent for HIV testing and pre- and post-test counseling associated with testing and defines patients or subjects to be tested for the HIV. Section 121 contains provisions authorizing the disclosure of HIV status, without patient consent and under certain specific conditions, to Federal, State or local public-helath authorities, or to an individual's spouse or sexual partner.

3. ACTION:

a. The Veterans Administration will not conduct widespread testing for the HIV (Human Immunodeficiency Virus) unless specific funding to do so has been appropriated by Congress. Testing for the virus will be voluntary; will be conducted only with the prior informed and written consent of the patient or subject and will be accompanied by pre- and post-test counseling.

b. Testing should be offered and made available to patients or subjects for whom health care or services are provided by the Veterans Administration and who are:

(1) Receiving treatment for intravenous drug abuse,

(2) Receiving treatment for a disease associated with the HIV, or

(3) At high risk for infection with the HIV.

Unless medically contraindicated, testing should be conducted for each patient or subject who requests the test.

c. Section 121 of the law, Confidentiality of Medical Records, addresses the confidentiality of medical records of patients or subjects tested for or infected with the HIV and the conditions under which disclosure of information related to the individual's testing or infection may be made. DM&S Circular 10-88-134 establishes policy related to this section and should be consulted for guidelines. Two issues should be noted:

(1) The addition of the medical records of patients or subjects who are tested for or infected with the HIV to the confidentiality provisions of 38 U.S.C. 4132, namely, those accorded to programs or activities related to drug abuse, alcoholism or alcohol abuse or sickle cell anemia. Penalties for unauthorized disclosure include a fine of up to $5,000 for the first offense and up to $20,000 for a subsequent offense.

(2) Disclosures may be made where the individual who was tested has provided a specific written consent; e.g., VA Form 10-5345, for such disclosure. Where such individual is deceased, a disclosure may be made on the request of the next of kin, executor or personal representative if such disclosure is needed by the survivor to obtain benefits.

(3) Disclosure without the specific written consent of the HIV tested or infected patients or subjects may be made under the following circumstances:

(a) In response to an appropriate request from a proper Federal State or local public health authority charged with the protection of the public health and to which Federal or State law requires disclosure of such information,

(b) To medical personnel to the extent necessary to meet the needs of a medical emergency,

(c) Where authorized by an appropriate court order,

(d) For research or audit purposes, including oversight by a Congressional Committee; however, redisclosure of such data is subject to further restrictions,

(e) To the appropriate component of the Armed Forces which is providing health care to the veteran,

(f) A physician or professional counselor may, under certain conditions, disclose information indicating a patient is infected with HIV to the spouse of the patient or subject and/or to an individual who has been identified by the patient or subject as a sexual partner during the course of professional counseling or testing. Disclosure may be made only under the following dconditions:

1. The physician or counselor has made a reasonable effort to counsel and encourage the patient or subject to voluntarily provide this information to the spouse or sexual partner, and the physician or counselor reasonably believes the patient or subject will not provide the information to the spouse or sexual partner, and that

2. Disclosure is necessary to protect the health of the spouse or sexual partner.

Disclosure may be made by a physician or counselor who has not been the primary caregiver only when the primary physician or counselor is unavailable due to prolonged absence or termination of employment.

d. VA Form 10-0121 will be used as the form for each patient or subject to consent to be tested. One copy of this form is attached for local reproduction until such time as you receive an initial distribution of printed forms. The completed VA Form 10-0121 will be maintained in the patient's medical record.

e. All elements of the written informed consent form should be verbally explained in detail during pre-test counseling. Pre-test counseling should include, but not be limited to, the following information:

(1) The meaning, sensitiivity and specificity of the HIV tests,

(2) The potential social ramifications of a positive test result,

(3) Policies and guidelines for confidentiality of the test results,

(4) Policy on non-discrimination in health care services for patients with HIV infection and the health care services available in the Veterans Administration,

(5) Policy and guidelines on disclosure to public health authorities,

(6) Policy on disclosure to spouse and/or sexual partner as defined in paragraph c.(3)(f),

(7) Measures to be taken for prevention of HIV transmission, and

(8) Information relative to authorized disclosures, either with or without consent, of HIV test or treatment records.

f. Post-test counseling should be adapted to both the test result and the particular needs of the individual patient or subject.

(1) Counseling for a negative result should include, but not be limited to, the validity of the negative result if the patient is in a group at high risk for HIV infection, possible retesting and reinforcement of risk reduction behaviors.

(2) If the test results are positive, post-test counseling should include, but not be limited to, reinforcement of the availability of health care services within the Veterans Administration and community and public health resources; the advantages of notification of spouse or other sexual partners of possible exposure to the HIV and reinforcement of preventive HIV transmission measures to be taken by the patient or subject.

g. All elements of the counseling process should be documented on the progress notes of the medical chart. Pre-test documentation should include, but not be limited to, the following elements:

(1) The fact that pre-test counseling was conducted,

(2) The date and time written consent was given,

(3) A brief description of the content covered in counseling, as for example, the items listed in paragraph e,

(4) The patient's response to and participation in the counseling session(s),

(5) The patient's mental status at the time of counseling,

(6) A brief assessment of the patient's comprehension of the significance, meaning and ramifications of the test, and

(7) The fact that the patient freely consented to testing.

h. Post-test documentation should include, but not be limited to:

(1) The results of the test,

(2) A brief discussion of the content covered in the counseling,

(3) An assessment of the patient's emotional/mental status,

(4) Referrals made, if any, and plans for future services.

If spouse or partner notification is conducted by the physician or counselor, documentation in in the progress note should include the reasons for notification, the process of notification and the referral of the spouse or sexual partner, as appropriate, to community or public health resources.

4. REFERENCES:

a. Public Law 100-322, Veterans' Benefits and Services Act of 1988, Sections 121 and 124.

b. DM&S Circular 10-88-134, "Sec. 121, Pub. L. 100-322, Confidentiality of Medical Records of Patients Infected with Human Immunodeficiency Virus (HIV)".

5. RECISSIONS: This circular expires December 14, 1989.

6. FOLLOW-UP RESPONSIBILITY: Director, AIDS Program Office (10B/AIDS).

/s/
JOHN A. GRONVALL, M.D.
Chief Medical Director

Attachment

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CONSENT FOR HUMAN IMUNODEFICIENCY VIRUS (HIV) ANTIBODY TESTING

I have asked or been asked to have my blood tested for antibodies to the HIV (Human Immunodeficiency Virus), the virus which causes AIDS. It is not a test for AIDS. If I do have antibodies to the virus (a POSITIVE TEST), this means that I have been infected with the virus. If I do not have antibodies (a NEGATIVE test) but am in a group of people who are at high risk for AIDS (people who have had multiple sex partners or who share needles when using drugs), this does not mean that I will not become infected in the future. In fact, I may already be infected but have not yet had time to develop antibodies.

I have been told that the blood tests for antibodies to the virus are not foolproof. In a small number of people, other things such as another virus or disease may wrongly cause a positive test. This is called a false positive test. It is also possible to have a false negative test. In this case, I do have the antibodies to the virus but the test did not show this. If the first test on my blood is positive, the test will be repeated. If positive again, a different test will be conducted. These tests will all be done on the blood taken after I sign this consent.

I have been told that the HIV is spread through blood from an infected person. It is also spread by having sex with an infected person. I understand that if my test is positive, I can spread the infection to others. I must not give blood or plasma or donate my organs or sperm if I am positive.

If I have a positive test, I should explain this to any sexual partner. If I am unable to tell my spouse or any other sexual partner whom I have identified, my doctor or counselor may do so but only to protect their health.

If I have a positive test, my case may be reported to public health agencies. However, the public health staff may only use or give out that information for the public health purpose for which it was given. Otherwise, information about my HIV testing cannot be revealed to anyone outside the VA without my written permission, or, a court order, a medical emergency, for research, Congressional oversight, or audit purposes, or for medical treatment provided to me by the Armed Forces.

I have been told that the results of my test (positive or negative) will be in my medical record. I understand that any VA employee who improperly releases information about my HIV testing is subject to a fine. Even though I understand every effort will be made to protect the results of my test, I also understand that disclosure of a positive test result can lead to discrimination in housing, jobs, and other areas in some communities.

I have been counseled about the HIV test and have been given a chance to ask questions. I understand what a positive and a negative test means. I understand that the test is voluntary and that I will still receive care from the VA if I refuse to have the test done.

Therefore, I give my permission for my blood to be tested for HIV antibodies.

______________________________________ ____________________
PATIENT or LEGAL GUARDIAN DATE

______________________________________ ____________________
WITNESS DATE

VA FORM 10-0121
DEC 1988

VETERANS ADMINISTRATION CENTRAL OFFICE
SELECTED AIDS DIRECTIVES

Identification of Document	Date of Document
IL 10-83-34 Chief Medical Director's Letter - Acquired Immune Deficiency Syndrome (AIDS)	9/2/83
IL 11-83-26 Professional Services Letter - Acquired Immune Deficiency Syndrome (AIDS) in VA Facilities	12/22/83
Circular 10-85-181 Testing of Donor Blood and Plasma for Antibodies to AIDS (ANTI-HTLV III)	11/21/85 *11/20/86
IL 11-85-12 Clinical Affairs Letter - HTLV-III Testing in VA Facilities	12/31/85
Circular 10-86-7 Recommendations for Preventing Transmission of Infection with Human T-Lymphotropic Virus Type III/Lymphadenopathy - Associated Virus(HTLV-III/LAV) in the Workplace	1/24/86 *12/31/86
IL 11-86-15 Clinical Affairs Letter - Psychosocial Treatment of Patients with Acquired Immune Deficiency Syndrome (AIDS)	9/30/86
DVB Circular 21-86-131 Acquired Immune Deficiency Syndrome (AIDS)	1/25/86
Circular 10-87-64 Follow-up on VA Patients Who Have Received Blood Products from Donors Who Have Tested Positive for Antibody to HTLV-II/LAV	7/8/87 *7/7/88
Circular 10-87-65 Testing Transfusion Recipients for HIV (Human Immunodeficiency Virus) Antibodies	7/8/87 *7/7/88
Circular 10-87-79 Prevention of Transmission of Infection with Human Immunodeficiency Virus in the Workplace	8/3/87 *8/2/88

IL 10-87-24 10/15/87
Informed Consent and Testing for HIV Antibodies

Circular 10-87-140 12/4/87
Case Reporting of AIDS According to the New *12/2/88
Surveillance Definition (RCS 10-0116)

IL 10-88-2 1/28/88
HIV Testing Experience in VA Health Care Facilities: National Survey Results

Circular 10-87-79, Supplement No. 12/4/88
Prevention of Transmission of Infection with *2/3/89
HIV and Other Blood borne Agents in the Workplace (by the use of Universal Precautions)

IL 14-88-1 3/29/88
Announcement of the VA's National Education Plan on AIDS (Acquired Immunodeficiency Syndrome)and HIV (Human Immunodeficiency Virus) Infection,FY 1980-90

*Expiration Date
Veterans Administration

Department of Medicine
and Surgery

Washington D.C. 2042

Veterans
Administration

IL 10-83-34

September 2, 1983

CHIEF MEDICAL DIRECTOR'S LETTER

In Reply Refer To:

TO: Regional Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Acquired Immune Deficiency Syndrome

1. The purpose of this letter is to provide guidance to those facilities treating patients with Acquired Immune Deficiency Syndrome (AIDS).

2. Definition: The VA accepts the Center for Diseases Control (CDC) definition of AIDS, which is "a case with a disease at least moderately predictive of a defect in cell-mediated immunity occurring in a person with no known cause for diminished resistance to that disease." These diseases include Kaposi's sarcoma (KS), Pneumocystis carinii pneumonia (PCP) and other opportunistic infections (OOI). The other opportunistic infections include:

Pneumonia, meningitis or encephalitis due to one or more of the following:

- Aspergillosis
- Candidiasis
- Cryptococcosis
- Cytomegalovirus
- Nocardiosis
- Strongyloidiasis
- Toxoplasmosis
- Zygomycosis
- Atypical mycobacteria (species other than tuberculosis or lepra)

Esophagitis due to:
- Candidiasis
- Cytomegalovirus
- Herpes simplex virus

Progressive multifocal leukoencephalopathy

Chronic enterocolitis (more than 4 weeks) due to cryptosporidiosis

Unusually extensive mucocutaneous herpes simplex of more than 5 weeks duration

3. Epidemiology: The disease appears to be concentrated in specific high risk groups:

- Homosexual or bisexual males
- Intravenous drug users
- Persons born in Haiti, now living in the U.S.
- Hemophiliacs

Approximately 6% of cases occur in persons who cannot be placed in any of the above categories. Most of the cases occur in residents of large cities with New York reporting 45% of all known cases, San Francisco 10%, and Los Angeles 6%, although cases have been reported from 38 states, the District of Columbia and Puerto Rico. As of July 11, 1983, 1831 patients meeting the CDC definition had been reported to health authorities. The cause of AIDS is unknown, but it appears to be caused by an agent transmitted by intimate sexual contact, through contaminated needles or less commonly by percutaneous innoculation of infectious blood or blood products. There is no evidence of airborne spread or risk from casual contact. While cases have been reported in health workers, none gave a history of caring for an AIDS patient or having contact with blood of an AIDS patient.

4. Precautions: Since the patterns of AIDS transmission resemble the distribution of disease and modes of spread of hepatitis B virus, it is recommended that all hospital personnel use the same precautions as those used for patients with hepatitis B virus infection in which blood and body fluids which may have been contaminated by blood are considered infective.

Blood and organs of AIDS patients should not be donated. The subject of blood bank policies is addressed in two Professional Services Letters: (11-83-10 and 11-83-12).

Hepatitis B precautions are also recommended for persons with: OOI not associated with underlying immunosuppressive disease or therapy; KS (if under age 60); chronic generalized lymphadenopathy; unexplained weight loss or prolonged FUO (in persons thought to be at risk of AIDS); and in persons hospitalized for evaluation of possible AIDS. These precautions have been published in the November 5, 1982 edition of Morbidity and Mortality Weekly Review and VA medical centers should see that their clinical and laboratory staff are familiar with them.

The diagnosis of AIDS in a hospital employee does not preclude continued employment in a VA medical center. However, the employee should be instructed to take some health care precautions as those recommended for persons who have had hepatitis B. Since employees with AIDS are at risk of opportunistic infection, they should review with their personal physician the nature of their patient care contacts in order to minimize the risks to themselves. Adjustment in duties will be based on medical certification.

in the same

Healthy personnel should not be excused from delivering care to AIDS patients at their own request. However, those personnel at special risk of infection should discuss their work responsibilities with their personal physician and the VA medical center personnel health physician. Adjustment in duties may be arranged, if possible, within the employee's service, at the discretion of the Director and Chief of Staff.

Those stations treating AIDS patients should amend their Infection Control Manual(s) to include AIDS.

5. Reporting. In May 1983, state and territorial epidemiologists at their annual conference recommended that AIDS be added to the list of notifiable disease in all states. Several states have already acted on this recommendation and others are in the process of doing so. Some are using an extensive 4 page form (CDC 59.3 REV 4-83) containing very specific clinical and social/life style information considered by some patients and health care workers to be unduly intrusive. The VA General Counsel has reviewed the document and has recommended that reporting cases without names but with the patient's initials and last four digits of his/her social security number would overcome any objections based on the Privacy Act.

Because of the national interest and clinical and budgetary implications of the diagnosis and treatment of AIDS, there is interest in VACO in assessing the extent of the disease in the VA. Special reporting requirements for AIDS are outlined in Circular 10-83-146.

6. Research: AIDS has been the subject of a great deal of media coverage and intense research interest. VA investigators are involved in this area, as are many other groups throughout the country. Requests for participation in studies have been received by local VA medical centers and VACO. The decision to participate will be a local one after the protocol has been approved by the local R&D Committee and the Human Subjects Subcommittee. Traditionally the VA has cooperated with CDC when possible on problems with public health significance.

The Hospital Infections Program at CDC has initiated a study at selected hospitals, in co-operation with several state health departments, of health-care personnel who have had documented parenteral or mucous membrane exposure to blood of definite or suspected AIDS patients. This study is now being expanded to include additional centers. Hospital epidemiologists, infection control nurses, infectious disease physicians and Employee Health Service personnel should be aware of this study. If they know of parenteral or mucous membrane exposure to blood of definite or suspected AIDS patients and desire more information about the study, they should contact Dr. Susan Mather, FTS 389-2450.

7. AIDS Committee: An ad hoc committee has been established in VACO under the Co-chairmanship of Dr. Howard D. Cohn, Deputy ACMD for Clinical Services and Dr. Richard Greene, Director of Medical Research Service, to coordinate the activities of various services, evaluate requests for research, review proposed policies, and serve as a focal point for problems and discussions related to AIDS. Committee members represent Medical, Surgical, Mental Health and Behavioral Sciences, Nursing and Laboratory Service, Medical Research and Building Management. Building Management Service is preparing a Technical Advisory

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for their field people which will contain background and specific procedures for building management personnel to follow in their contacts with AIDS patients. Infectious Disease personnel should be familiar with this publication and cooperate in any necessary staff education. Informal reports from medical centers inside and outside recognized epi-centers of AIDS indicate that patients are being treated by VA health care workers on a regular basis.

8. A list of selected references is attached for your information.

9. Questions about this letter should be directed to Dr. Howard D. Cohn (FTS 389-3560), Dr. Richard Greene (FTS 389-5041) or Dr. Susan Mather (FTS 389-2450).

DONALD L. CUSTIS, M.D.
Chief Medical Director

Attachment

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ATTACHMENT A

September 2, 1983

SELECTED REFERENCES - AIDS

A. The knowledge base and the literature on AIDS is expanding so rapidly that bibliographies are quickly outdated. However, the National Institutes of Allergy and Infectious Diseases (NIAID/NIH) maintains an updated bibliography on AIDS and Kaposi's sarcoma. Copies and updates can be obtained by writing:

AIDS Bibliography
NIAID
9000 Rockville Pike
Building 5, Room 135
Bethesda, MD 20505

B. At this time, the most current information is to be found in Morbidity and Mortality Weekly Report.

1. CDC. Update: Acquired Immunodeficiency Syndrome (AIDS) - United States. MMWR 32:389-391, Aug. 5, 1983.
2. CDC. An Evaluation of the Acquired Immunodeficiency Syndrome (AIDS) Reported in Health-Care Personnel-United States. MMWR 32:358-360, July 15, 1983.
3. CDC. Acquired Immune Deficiency Syndrome (AIDS): Precautions for Clinical and Laboratory Staffs. MMWR 31:577-580, November 5, 1983.

C. Other References

1. Durack, D. T: Opportunistic Infectious and Kaposi's Sarcoma in homosexual men. N Eng J Med 305: 1465-67, 1981.
2. Greene, J.B., Sidhu, G.S., Lewin, S., et al. Mycobacterium avium-intracellulare: a cause of disseminated life-threatening infection in homosexuals and drug abusers. Ann Int Med 97:539-46, 1982.
3. Rubin, R.H., Infection in the Immunosuppresed Host: Acquired Immuno deficiency Syndrome. Scientific American Medicine 7:X: 7-8

Department of Medicine and Surgery
Washington D.C. 20420

Veterans Administration

IL 11-83-26

December 22, 1983

In Reply Refer To 111

PROFESSIONAL SERVICES LETTER

TO: Regional Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Acquired Immune Deficiency Syndrome (AIDS) in VA Facilities

1. The purpose of this letter is to summarize the results of the survey of all cases of AIDS being diagnosed and/or treated in VA health care facilities conducted by means of Circular 10-83-146, dated September 2, 1983.

2. There have been a total of 182 cases of AIDS reported by 46 of 169 facilities on record as of November 1, 1983. Of these, 96 are known to have died. Twenty-two (22) stations reported single cases, while only 8 VA medical centers reported more than 5 cases each. Expected concentration occurred on the east and west coasts. Seventy-five (75)cases were reported in 4 metropolitan New York area hospitals. San Francisco and Los Angeles reported 11 and 15 cases respectively. The other cases were scattered throughout all the medical regions with only 5 medical districts in the central U.S. (Districts 10, 11, 15, 22 and 23) reporting no cases of AIDS. Two facilities reported having employees with AIDS.

3. We are aware that the staff in VA medical centers and outpatient clinics are giving these patients the same compassionate, high quality care that they accord other patients despite the well publicized uncertainty which surrounds transmission of the disease. There continues to be no evidence of transmission by casual contact or airborne spread and no cases of AIDS in health-care or laboratory personnel which can be definitely ascribed to specific exposure. Centers for Disease Control (CDC) has published precautions for clinical and laboratory personnel who work with AIDS patients, which were cited in an earlier CMD Letter on AIDS (IL 10-83-34). Since that letter, there have been additional precautions specifically targeted to those providing dental care and those performing post mortem examinations published. 1/ These should be brought to the attention of the affected personnel caring for patients who either (1) meet the existing surveillance definition of AIDS; (2) have chronic, generalized lymphadenopathy, unexplained weight loss, and/or prolonged unexplained fever when the patient's history suggests an epidemiologic risk for AIDS; or (3) are hospitalized with possible AIDS:

A. Precautions for Dental-Care Personnel

(1) Personnel should wear gloves, masks, and protective eyewear when performing dental or oral surgical procedures.

(2) Instruments used in the mouths of these patients should be sterilized after use.

B. Precautions for Persons performing Post-mortem examinations

(1) Deceased persons who fall into one of the above categories should be identified and the identification remain with the body.

(2) Hepatitis B precautions should be observed before, during, and after the post-mortem examination. All persons involved in performing the autopsy should wear double gloves, masks, protective eye wear, gowns, waterproof aprons, and waterproof shoe coverings. Instruments and surfaces contaminated during the post mortem examination should be handled as potentially infective.

4. Any questions about this letter should be directed to Dr. Susan Mather, Medical Service. (FTS 389-2450).

CARL W. HUGHES, M.D.
Assistant Chief Medical Director
for Professional Services

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REFERENCE

1/ CDC: Morbidity and Mortality Weekly Report. September 2, 1983, Vol. 32., No. 34, p. 450

CIRCULAR 10-85-181
November 21, 1985

TELEGRAPHIC MESSAGE

NAME OF AGENCY VACO, WASHINGTON, DC	PRECEDENCE ACTION P INFO.	SECURITY CLASSIFICATION
ACCOUNTING CLASSIFICATION	DATE PREPARED 10/1/85	FILE
FOR INFORMATION CALL		
NAME GRACE H. GUIN, M.D.	PHONE NUMBER 389-2679	TYPE OF MESSAGE ☐ SINGLE ☐ BOOK ☒ MULTIPLE ADDRESS

THIS SPACE FOR USE OF COMMUNICATION UNIT

MESSAGE TO BE TRANSMITTED *(Use double spacing and all capital letters)*

TO. DIRECTORS, ALVAMC, AND REGIONAL OFFICES WITH OUTPATIENT CLINICS,
(REGIONAL DIRECTORS)
00/DM&S CIRCULAR 10-85-181 (DTD: 11-21-85)

SUBJ: TESTING OF DONOR BLOOD AND PLASMA FOR ANTIBODIES TO AIDS
(ANTI - HTLV-III)

1. THE PURPOSE OF THIS COMMUNICATION IS TO CLARIFY THE CURRENT POSITION OF THE VETERANS ADMINISTRATION DEPARTMENT OF MEDICINE AND SURGERY ON THE TESTING OF DONOR BLOOD, OBTAINED EITHER FROM OUTSIDE DONOR SERVICES OR FROM VA MEDICAL CENTER DONOR ACTIVITIES, FOR THE PURPOSE OF THERAPEUTIC TRANSFUSION IN VA PATIENTS.

2. THE FOOD AND DRUG ADMINISTRATION (FDA), OFFICE OF BIOLOGICS RESEARCH AND REVIEW, AND THE PUBLIC HEALTH SERVICE (PHS) HAS ISSUED THE FOLLOWING INTERAGENCY RECOMMENDATIONS THAT:

A. ALL DONOR BLOOD AND PLASMA INTENDED FOR TRANSFUSION BE TESTED FOR ANTIBODIES TO HTLV-III.

B. ALL PROSPECTIVE DONORS DRAWN BY VA PERSONNEL WILL BE INFORMED THAT THEIR BLOOD WILL BE TESTED FOR ANTIBODIES TO HTLV-III.

PAGE NO 1	NO OF PGS 4	SECURITY CLASSIFICATION

TELEGRAPHIC MESSAGE

NAME OF AGENCY	PRECEDENCE ACTION INFO	SECURITY CLASSIFICATION
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MESSAGE TO BE TRANSMITTED *(Use double spacing and all capital letters)*

TO:

C. REPEATEDLY POSITIVE ELISA TEST RESULTS, OR OTHER POSITIVE TESTS (HEPATITIS, SYPHILIS), REQUIRE THAT THE DONOR ACTIVITY NOTIFY THE DONOR OF THESE RESULTS.

D. ALL POSITIVE UNITS MUST NOT BE TRANSFUSED OR MANUFACTURED INTO OTHER PRODUCTS CAPABLE OF TRANSMITTING INFECTIOUS AGENTS.

3. MOST VETERANS ADMINISTRATION MEDICAL CENTERS CURRENTLY OBTAIN DONOR BLOOD FROM NON-VA SOURCES SUCH AS THE AMERICAN RED CROSS BLOOD PROGRAM (ARC), THE AMERICAN ASSOCIATION OF BLOOD BANKS (AABB), THE COUNCIL OF COMMUNITY BLOOD CENTERS (CCBC), AND OTHER ACCREDITED DONOR ACTIVITIES, AS WELL AS FROM SELECTED MILITARY INSTALLATIONS. SEVERAL VAMCS MAINTAIN FULL-SERVICE DONOR PROGRAMS. IN ADDITION, VAMCS WITH OR WITHOUT DONOR PROGRAMS MAY ON OCCASION DRAW DONOR BLOOD FOR EMERGENT USE, AUTOLOGOUS OR DIRECTED TRANSFUSION, ALTHOUGH THESE ACTIVITIES ARE INFREQUENTLY PERFORMED.

4. ON AUGUST 14, 1985 THE ASSISTANT SECRETARY OF DEFENSE ISSUED THE FOLLOWING STANDARDIZED REPORTING REQUIREMENTS FOR BLOOD COLLECTION AGENCIES ON MILITARY INSTALLATIONS: "EFFECTIVE SEPTEMBER 1, ALL

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TELEGRAPHIC MESSAGE

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TO:

AGENCIES CONDUCTING BLOOD COLLECTION OPERATIONS ON MILITARY INSTALLATIONS WILL COMPLY WITH THE FOLLOWING REQUIREMENTS:

A. ALL POTENTIAL DONORS MUST BE INFORMED THAT, TO ASSURE A SAFE BLOOD SUPPLY, TESTING IS PERFORMED FOR THE PRESENCE OF HEPATITIS-B SURFACE ANTIGEN, HTLV-III ANTIBODY, AND SYPHILIS.

B. THE MAJOR NATIONAL CIVILIAN AGENCIES COLLECTING BLOOD ON MILITARY INSTALLATIONS HAVE INDICATED THEIR INTENT TO ASK PROSPECTIVE ACTIVE DUTY DONORS TO SIGN A STATEMENT GIVING INFORMED CONSENT FOR NOTIFICATION TO MILITARY DOCTORS OF POSITIVE RESULTS AND TO INFORM THOSE WHO DO NOT WISH TO GIVE CONSENT THAT THEY MAY LEAVE THE BLOOD DONATION SITE WITHOUT PROVIDING AN EXPLANATION.

C. THE BLOOD COLLECTION AGENCY WILL INFORM THE COGNIZANT LOCAL MILITARY MEDICAL AUTHORITY OF ANY POSITIVE FINDINGS INDICATIVE OF THE PRESENCE OF HEPATITIS-B SURFACE ANTIGEN, HTLV-III ANTIBODY AND SYPHILIS IN BLOOD DONATED BY ACTIVE DUTY PERSONNEL."

5. TO ASSURE THAT A SAFE DONOR BLOOD SUPPLY IS OBTAINED FOR ALL VA PATIENTS, THE RECOMMENDATIONS OF THE FDA AND PHS WILL BE FOLLOWED,

PAGE NO	NO OF PGS	SECURITY CLASSIFICATION
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CIRCULAR 10-85-181
November 21, 1985

TELEGRAPHIC MESSAGE

NAME OF AGENCY	PRECEDENCE ACTION. INFO	SECURITY CLASSIFICATION
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MESSAGE TO BE TRANSMITTED *(Use double spacing and all capital letters)*

TO:

EFFECTIVE IMMEDIATELY, UNTIL FURTHER NOTICE. HOWEVER, IT WILL NOT BE NECESSARY FOR VA MEDICAL CENTERS TO RE-TEST DONOR BLOOD OR PLASMA UNITS (OR OTHER BLOOD FRACTIONS PREPARED FROM PLASMA OR BLOOD, VIZ. PLATELETS, PACKED RED BLOOD CELLS, ETC.) IF IT HAS ALREADY BEEN TESTED BY THE AGENCY THAT PROCURED THE BLOOD.

A. ANY BLOOD OR BLOOD PRODUCT PROCURED BY VA PERSONNEL IN ANY VAMC OR FROM OUTSIDE SOURCES SUCH AS MILITARY INSTALLATIONS MUST BE TESTED FOR ANTIBODIES TO HTLV-III VIRUS, HEPATITIS B SURFACE ANTIGEN AND SYPHILIS BY CURRENT METHODS ACCEPTABLE TO THE CENTERS FOR DISEASE CONTROL. BLOOD DRAWN FOR DIRECTED TRANSFUSIONS MUST ALSO BE SIMILARLY TESTED.

B. AUTOLOGOUS BLOOD, IF TRANSFUSED INTO ITS DONOR NEED NOT BE TESTED FOR ANTIBODIES TO HTLV-III VIRUS, HEPATITIS B SURFACE ANTIGEN OR SYPHILIS. HOWEVER, IF THE AUTOLOGOUS UNIT IS NOT USED BY ITS DONOR, BUT IS TO BE TRANSFUSED TO A PATIENT OTHER THAN ITS DONOR, THE UNIT MUST BE TESTED AS INDICATED IN 2A ABOVE.

C. THIS CIRCULAR EXPIRES NOVEMBER 20, 1986. 113/10A.

John A Gronvall M.D.

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Department of Medicine
and Surgery

Washington D C 2042

Veterans
Administration

IL 11-85-12

December 31, 1985

In Reply Refer To

CLINICAL AFFAIRS LETTER

TO: Regional Directors; Directors, All DM&S Field Activities

SUBJ: HTLV-III Testing in VA Facilities

1. The purpose of this Letter is to provide guidance to VA health care facilities concerned about clinical uses of the HTLV-III antibody test.

2. Background:

a. The etiologic agent of the acquired immune deficiency syndrome (AIDS) is human T-cell lymphotrophic virus type III (HTLV-III), also known as lymphadenopathy associated virus (LAV) and AIDS related virus (ARV). HTLV-III has a cytotoxic effect on T-lymphocytes of the helper type. The infections and tumors which are the cause of death for AIDS patients result from the incompetent immune system. Over 90% of patients with AIDS are positive for HTLV-III antibodies when screened. Among seropositive persons, the risk for developing AIDS may vary depending on the population group studied and other less well-defined factors. Preliminary data from cohorts of homosexual males followed two to five years indicates that between 5% and 20% of persons with detectable HTLV-III antibodies may go on to develop AIDS. However, information pertaining to homosexual males may not be translatable to other populations or risk groups. The long term implications of infection to any individual are unknown. Furthermore, the absence of the antibody in high risk individuals is not insurance that the individual is virus-free since virus has been isolated from antibody negative individuals in high risk groups. Likewise, biological false positives exist. The Public Health Service placed a very high priority on expediting the development and approval of the HTLV-III antibody test so that it could be used to screen blood and plasma prior to use, thus achieving an extremely important public health goal. However, it is important to stress to both physicians and patients that the HTLV-III antibody test is not a test for AIDS.

b. The antibody screening test developed for blood banks uses the ELISA (enzyme-linked immunosorbent assay) technology. The Public Health Service recommends that additional testing be done to clarify the significance of the screening test. The Western blot test has been used extensively for this purpose but is still considered a research tool.

3. Counseling and Evaluation of the Seropositive Individual:

a. Patients may present with positive HTLV-III screening tests obtained at blood donor centers or through community and military screening programs.

The clinical significance of the test should be discussed including the occurrence of false positives. It should be stressed that the antibody test is NOT a test for AIDS. However, if the physician is satisfied that the individual is seropositive, further clinical evaluation is indicated. Other conditions resulting from HTLV-III infection are the lymphadenopathy syndrome and AIDS related complex (ARC). The lymphadenopathy syndrome is characterized by persistent, unexplained lymphadenopathy in several extra-inguinal lymph node groups. Progression to overt AIDS appears to occur in approximately 10% of the cases. ARC is a clinical and laboratory syndrome characterized by minor conditions (e.g., oral thrush) associated with immune suppression and laboratory evidence of the same. AIDS presentation generally follows four major patterns:

(1) A febrile prodrome of weeks to months followed by opportunistic infection
(2) Abrupt onset of opportunistic infection
(3) Presentation with Kaposi's sarcoma
(4) Progression from ARC

b. A careful history and physical are necessary to evaluate the multisystem complex of AIDS. Laboratory tests are also helpful in evaluating signs and symptoms but should be based on clinical findings. A thorough review is beyond the scope of this letter and selected references are recommended.

c. Long term follow-up with careful assessment of symptomatology is in order for seropositive individuals.

d. CDC has published the following information and advice which is recommended to be provided to individuals judged to be infected:

(1) The prognosis for an individual infected with HTLV-III over the long term is not known. However, data available from studies conducted among homosexual men indicate that most persons will remain infected.

(2) Although asymptomatic, these individuals may transmit HTLV-III to others. Regular medical evaluation and follow-up is advised, especially for individuals who develop signs or symptoms suggestive of AIDS.

(3) Refrain from donating blood, plasma, body organs, other tissue, or sperm.

(4) There is a risk of infecting others by sexual intercourse, sharing of needles and, possibly, exposure of others to saliva through oral-genital contact or intimate kissing. The efficacy of condoms in preventing infection with HTLV-III is unproven, but the consistent use of them may reduce transmission.

(5) Toothbrushes, razors, or other implements that could become contaminated with blood should not be shared.

(6) Women with a seropositive test, or women whose sexual partner is seropositive, are themselves at increased risk of acquiring AIDS. If they become pregnant, their offspring are also at increased risk of acquiring AIDS.

(7) After accidents resulting in bleeding, contaminated surfaces should be cleaned with household bleach freshly diluted 1:10 in water.

(8) Devices that have punctured the skin, such as hypodermic and acupuncture needles, should be steam sterilized by autoclave before reuse or safely discarded. Whenever possible, disposable needles and equipment should be used.

(9) When seeking medical or dental care for intercurrent illness, these persons should inform those responsible for their care of their positive antibody status so that appropriate evaluation can be undertaken and precautions taken to prevent transmission to others.

(10) Testing for HTLV-III antibody should be offered to persons who may have been infected as a result of their contact with seropositive individuals (e.g., sexual partners, persons with whom needles have been shared, infants born to seropositive mothers).

4. Testing for HTLV-III Antibodies in VA Facilities:

a. Counseling should begin before the test is done and should be incorporated into any testing done by VA facilities. Individuals should be given information about the implications of the ELISA test before being tested, with particular emphasis on the significance of a positive test. The test should be ordered only when clinically indicated.

b. The HTLV-III antibody test should be considered a laboratory test useful in diagnosis but not diagnostic of AIDS per se. Except in donor programs, it is not a screening test. The confidentiality of test results is essential because unauthorized disclosure could lead to serious social and employment conquences, including loss of employment or insurability. For this reason, coupled with the fact that the test is officially sanctioned by FDA only for screening blood donations, some medical centers have chosen not to put HTLV-III test results on the chart. This contrasts with established medical records policy, and is not V.A. policy. The Privacy Act of 1974, 5 U.S.C. § 552a, Subsection (e)(5) requires that an agency maintain all records, which are used in making any determinations about an individual, with such accuracy, relevance, timeliness and completeness as is reasonably necessary to assure fairness to the individual. Since the HTLV-III test appears to meet these standards, the results belong in the medical record. VA medical centers should do everything possible to assure the confidentiality of all medical records, and each medical center should have a written policy on the handling of HTLV-III antibody test results.

5. Additional Recommendations and Summary:

a. AIDS provides a challenge to the medical community on many fronts: scientific, economic and social. Dealing with HTLV-III testing is further complicated by an incomplete knowledge base but there are some basic premises under which DM&S will operate:

(1) Continuing education is imperative. Physicians have a responsibility to monitor the fast-moving medical literature on HTLV-III and AIDS to assure that optimal care is provided. CDC's Morbidity and Mortality Weekly Report is a useful aid in keeping up-to-date.

(2) Staff education is equally important to assure protection to care givers and promote an environment where optimal care may be provided.

(3) Blood and body fluid precautions are recommended for HTLV-III antibody positive patients as well as those with AIDS.

(4) It is expected that VA employees will provide clinically sound, compassionate care to AIDS patients and suspected HTLV-III carriers. This care will include any necessary surgery or dental care, and finally, post-mortem examinations when indicated.

(5) Employees with AIDS will be evaluated on a case-by-case basis to minimize risks to themselves and patients.

6. In summary, the occurrence of AIDS and HTLV-III infection in VA medical centers should heighten the awareness of all staff to the necessity of strict adherence to sound infection control principles and to the maintenance of confidentiality in patients' medical records. These are well established parts of sound hospital management, but the crisis in health care precipitated by AIDS serves to re-emphasize their importance.

MARK W. WOLCOTT, M.D.
ACMD for Clinical Affairs

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ATTACHMENT A

IL 11-85-12
December 31, 1985

HTLV-III Testing in VA Facilities

Selected References

A. The National Institutes of Allergy and Infectious Diseases (NIAID/NIH) maintains an updated bibliography on AIDS. Copies and updates can be obtained by writing:

AIDS Bibliography
NIAID
900 Rockville Pike
Building 5, Room 135
Bethesda, Maryland 20505

B. The most current information is to be found in Morbidity and Mortality Report.

1. CDC. Reports on AIDS, published in the Morbidity and Mortality Weekly Report, June 1981 through June 1985. March 1985.

2. CDC. Update: Acquired Immunodeficiency Syndrome in San Francisco Cohort Study, 1978-1985. MMWR 34:573-75, Sept. 27, 1985.

3. CDC. Update: Evaluation of HTLV-III/LAV infection in Health Care Personnel - United States. MMWR 34:575-578, Sept. 27, 1985.

4. CDC. Recommendations for Preventing Possible Transmission of HTLV-III/LAV from Tears. MMWR 34:533-534, Aug. 30, 1985.

C. Other References

1. AMA Council on Scientific Affairs. Status Report on the Acquired Immunodeficiency Syndrome: Human T-Cell lymphotrophic Virus Type III Testing. JAMA 254:1342-1345, Sept 13, 1985.

2. Carlson, J.R., Bryant, M.L., Hinrichs, S.H. et al. AIDS Serology Testing in Low- and High-Risk Groups. JAMA 253:3403-3408, June 21, 1985.

3. Devita, V.T., Jr., Hellman, Rosenberg, A. (Eds.) AIDS, Lippincott, Philadelphia, 1985.

4. Weiss, S.H., Goedert, J.J., Sarngadharau, M.G., et al. Screening Test for HTLV-III (AIDS Agent) Antibodies, Specificity, Sensitivity and Applications. JAMA 253:221-225, Jan. 11, 1985.

TELEGRAPHIC MESSAGE January 24, 1986

NAME OF AGENCY VETERANS ADMINISTRATION	PRECEDENCE PRIORITY ACTION INFO.	SECURITY CLASSIFICATION
ACCOUNTING CLASSIFICATION	DATE PREPARED 12/12/85	FILE
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NAME T. Brown	PHONE NUMBER X3097	TYPE OF MESSAGE ☐ SINGLE ☐ BOOK ☒ MULTIPLE ADDRESS

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TO:

DIRECTORS, ALVAMC AND REGIONAL OFFICES WITH OUTPATIENT CLINICS,

ALVAMOD, (REGIONAL DIRECTORS)

00/ THIS IS DM&S CIRCULAR 10-86-7 (DTD: 1/24/86)

SUBJ: RECOMMENDATIONS FOR PREVENTING TRANSMISSION OF INFECTION WITH HUMAN T-LYMPHOTROPIC VIRUS TYPE III/LYMPHADENOPATHY - ASSOCIATED VIRUS (HTLV-III/LAV) IN THE WORKPLACE

1. THE PURPOSE OF THIS CIRCULAR IS TO CALL ATTENTION TO THE INFORMATION AND RECOMMENDATIONS CONTAINED IN THE NOVEMBER 15, 1985, MMWR (CDC MORBIDITY AND MORTALITY REPORT/VOL. 34/NO. 45/ PP 681-694).

2. DM&S SUPPORTS THESE RECOMMENDATIONS WHICH SHOULD BE INCORPORATED INTO LOCAL POLICY CONCERNING HTLV-III/LAV INFECTION AND AIDS.

3. THIS DM&S CIRCULAR EXPIRES DECEMBER 31, 1986. 111/11 *w*

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John A Gronvall M.D.

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Veterans Administration

Department of Medicine
and Surgery

Washington DC 20420

Veterans
Administration

IL 11-86-15

SEP 3 0 1986

In Reply Refer To 122

CLINICAL AFFAIRS LETTER

TO : Regional Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics and Regional Offices with Outpatient Clinics (122)

SUBJ: Psychosocial Treatment of Patients with Acquired Immune Deficiency Syndrome (AIDS)

1. Background

a. AIDS is an infectious disease caused by the HTLV-III virus. Proposed new terminology is HIV (human immuno-deficiency virus). It is transmitted sexually, by blood and blood products and perinatally. As of May 1986, 20,305 people in the United States have been reported to have AIDS. One hundred times that number are estimated to have been exposed to the virus. Even more have been impacted as a "significant other" (i.e., friends, families, partners). The virus "destroys" the immune system and the patient is therefore susceptible to multiple infections and cancers involving multiple organ systems including the central nervous system. The AIDS epidemic continues and cases continue to be reported. After the diagnosis of AIDS is made 80% die within two years and almost 100% die within five years. Military personnel are currently being tested for exposure to the Human T-Cell Lymphotropic virus or HTLV-III. Many of those with AIDS, ARC or positive HTLV-III antibody tests will be seeking health care through the VA system following military service.

b. Central nervous system changes are frequently found in AIDS patients; various surveys report 30-88% rates of CNS complications. Recent studies reveal that the HTLV-III virus is neurotropic as well as lymphotropic. Symptoms range from mild to incapacitating, and can include headache, depression, mania, anxiety, difficulty with memory and problem solving, changes in personality, irritability, hallucinations, paranoia, and insomnia. Special attention should be provided during initial assessments to identify those neurologic and/or psychiatric problems which may be secondary to the biological effects of the HTLV-III virus on the brain.

2. Psychosocial Impact on Patient and Family

a. In addition to the "normal" emotional/psychological reaction of a patient with a terminal illness, AIDS patients may also experience social isolation, including withdrawal by family and friends, immediate loss of job, housing, etc. Their ability to cope with the impact of their illness may be impaired by decrease in self-esteem, feelings of guilt about life-style, perceived (real or imagined) rejection and fear by others.

- Homosexual patients are faced at the same time with conflicts related to the coincidental acknowledgement of sexual preference to family, friends and employers, as well as other issues related to their untimely terminal illness.

- Intravenous drug abusers, who demonstrate poor ability to cope premor and frequently live on the fringe of society without the usual social support, experience another spectrum of difficult psychosocial problems.

- AIDS Related Complex (ARC) patients are frequently medically ill and must deal with the ambiguity inherent in their diagnoses and prognosis. ARC patients are those who have positive HTLV-III and signs and symptoms of disease such as fever, fatigue, lymphadenopathy, often severe diarrheas, but have not had one of the major opportunistic infections or cancers that define AIDS.

- The "worried well" includes those in high risk groups who become chronically anxious regarding whether they have been exposed to or will contract AIDS.

- Patients with positive results from the HTLV-III blood test are in need of counseling.

- Families and significant others are simultaneously faced with the probable early death of a loved one and with learning how to deal with their reactions to the patient's sexual preference and/or I.V. drug abuse.

- Society at large is affected and needs help in responding to this disease in a rational and reasonably knowledgeable manner.

b. The gravity and complexity of the emotional/behavioral/social problems of these patients requires a coordinated, interdisciplinary inpatient and outpatient treatment approach. Since a failed immune system renders these patients vulnerable to multiple bouts of infection and a variety of cancers often requiring repeated hospitalizations, continuity of care and mobilization of the full range of community resources are essential. It may be beneficial to establish an interdisciplinary advisory committee to the Chief of Staff on treatment of AIDS patients. The committee may consist of representatives from Medicine, Infectious Disease, Oncology, Social Work, Nursing, Psychology, Psychiatry, Neurology, Chaplain, and other Services as appropriate.

3. Psychosocial Interventions

a. The nature of the illness and the multiple losses in both health and relationships that AIDS patients face make it desirable that continuity of care with the same providers be arranged. It may also be helpful to designate a specific clinician to respond to calls from staff, patients, and families.

b. Because of the complexity of psychosocial needs and problems of the AIDS patient, a social worker should be assigned to facilitate integration of VA/community health and social services and psychosocial treatment of patient and family. The social worker designated should be interested in and clinically comfortable with AIDS/ARC patients, be knowledgeable about AIDS, and as appropriate, be knowledgeable about drug abuse treatment. Working with AIDS patients makes heavy demands in virtually all components of social work practice (assessment; treatment; discharge planning; case management and community services coordination and development) and thus should be taken into consideration in making the assignment.

c. Areas for psychosocial intervention include the following:

(1) Individual and/or group psychotherapy and counseling to address issues related to (a) coping with the stigma and unknowns that the diagnosis of AIDS entails; (b) age (usually young); (c) losses including health, job, family and social supports, control, self-esteem, life-style and death of close friends; (d) isolation, withdrawal, and abandonment; (e) suicidal ideation, (f) death; and, (g) right to die, etc. Psychiatric consultation and treatment should be requested to deal with the dementing, affective and psychotic syndromes that develop in many of the AIDS/ARC patients.

(2) Support groups for families and significant others which can build or enhance crucial support systems for patients. Other services that may be beneficial include providing information regarding community resources; housing for patient visitors; respite care; and grief and bereavement counseling.

(3) Educational sessions for patients, families, and significant others may be provided individually or in a group format and should encourage open dialogue concerning this illness. Areas that should be addressed include information about the illness and its etiology; cautions and misconceptions concerning contagion, and a review of safe sexual practices. Much information is already available at the federal, state, and local levels and should be utilized in developing an educational program for patients, families/significant others, and staff. The VA medical center patient education committee should be consulted for review/approval of educational materials.

(4) Basic needs and concerns such as housing, financial assistance, transportation, legal matters, etc., should be considered with the patient, the family and significant others. (See Para. 4. Resource Identification and Utilization.)

(5) Discharge planning for AIDS patients is complex and requires considerable interdisciplinary coordination with patient/family/significant others, community health agencies, social agencies, and other organizations in developing plans that meet the medical and psychosocial needs of patients.

4. Resource Identification and Utilization

a. Following hospital care, patients with AIDS/ARC may be able to return home or to another living situation requiring less than skilled nursing care. They may be unable to work or attend to their daily needs, i.e., cooking, cleaning, bathing, driving to appointments, etc. Skilled nursing care in less than an acute setting may be indicated, but nursing homes and home health agencies may be unwilling and/or unable to serve AIDS patients. Social workers, public health nurses, and other health care workers are thus faced with the challenge of developing resources that would enable these patients to remain outside of the acute hospital while obtaining enough help to experience and sustain a reasonably safe and comfortable life. In developing an appropriate network of resources, consideration should be given to the use of available VA resources such as Hospital Based Home Care, a Nursing Home Care Unit, Substance Abuse Treatment programs, etc., as well as non-VA community resources.

b. The fear and stigma associated with AIDS make it necessary to increase efforts to educate community agencies about the disease in order to assure their cooperation in providing needed programs and services to this patient population. Resources required may include the following:

(1) Health care agencies and professionals who are willing to provide nursing home care, home health care, dental services, eye examinations, refractions, mental health, etc.

(2) Homemaker and personal assistance with meals, shopping, laundry, and health care.

(3) Transportation for medical and non-medical activities which cannot be provided by family, friends, or volunteers.

(4) Suitable (temporary or permanent) housing since landlords have often refused to allow the patient to return or the patient may not have had permanent housing.

(5) Religious support and counseling through such resources as churches or synagogues which have support groups for victims of AIDS and/or their families; interested and compassionate clergy who are willing to provide in-home counseling, administering of communion; assurance of confidentiality through privileged communication or the seal of the confessional, etc. Attention should be given to assure that referrals do not result in the patient being coerced or proselytized.

(6) Agencies and/or individuals identified to assist the patients with legal matters when needed. The diagnosis of AIDS/ARC has such profound emotional, psychological and social consequences for the patient, family and significant others, that it is usually difficult to face the issues concerning legal rights and choices for the person who is ill, and for others who are also involved. Questions arise concerning hospital visitation, authorization for medical tests and procedures and who is authorized to conduct the patient's business affairs should the patient become incompetent. Persons who might be involved in these issues include the

patient, family (biological and extended), friends, significant others, business associates, and health care personnel. Social workers can provide invaluable assistance to the patient, family and other significant persons in the patient's life by helping them deal with such issues before medical infirmities prevent effective legal planning. Areas of concern include: authority over property, authority over medical decisions, estate planning, burial, and body disposition.

(7) Leisure time/recreational activities in home and in the community which are important to help avoid isolation and stigma.

5. Patient/Staff Relationships

a. Basic to the patient/staff relationship is the ability of staff to be emotionally sensitive, non-judgmental and accepting of the patient. The threatening dramatic aspects of AIDS, the remaining unknowns and the fatal nature of the disease evoke unique feelings in the staff. Throughout the course of the illness, staff must deal with their own fear, anger, sense of helplessness, isolation and stress. Most of the patients' ages parallel that of the health care provider (20-40) eliciting feelings about their own vulnerability and mortality. Since the majority of the patients with AIDS are homosexuals or I.V. drug abusers, health care providers need to assess their attitudes toward these groups. Staff support groups and stress reduction workshops have proved helpful to those responsible for treating AIDS victims. In addition to the core treatment team, these groups may include dietetics, housekeeping, laboratory, dental, and radiology personnel.

b. Facilities engaged in treating AIDS patients should activate a committee, broadly representative of the hospital community, to develop aggressive education and intervention programs directed at all levels of hospital personnel. A station-wide education program about AIDS and the affected special population groups, does much to dispel myths and minimize anxiety and disruption. Some hospitals have developed special teams of personnel who are available to answer questions about AIDS and provide support to staff and patients. These teams could include clinicians such as an infection control nurse, social worker, psychologist, psychiatrist, physician, and nursing administrator.

MARK W. WOLCOTT, M.D.
ACMD for Clinical Affairs

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List of VA Publications

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REFERENCES

- IL 11-83-10 - Professional Services Letter - Joint Statement on Acquired Immune Deficiency Syndrome (AIDS) Related to Transfusion - March 16, 1983.
- IL 11-83-12 - Professional Services Letter - Acquired Immune Deficiency Syndrome (AIDS) - April 8, 1983.
- IL 11-83-26 - Professional Services Letter - Acquired Immune Deficiency Syndrome (AIDS) in VA Facilities - December 22, 1983.
- IL 10-83-34 - Chief Medical Director's Letter - Acquired Immune Deficiency Syndrome - September 2, 1983.
- IL 11-85-12 - Clinical Affairs Letter - HTLV-III Testing in VA Facilities - December 31, 1985.
- 10-86-7 - Circular - Recommendations for Preventing Transmission of Infection with Human T-Lymphotropic Virus Type III/ Lymphadenopathy - Associated Virus (HTLV-III/LAV) in the workplace - January 24, 1986.
- 10-86-96 - Circular - Case Reporting of Acquired Immune Deficiency Syndrome (AIDS) RCS 10-0116 - August 15, 1986.
- 18-13-19 - Building Management Service, DM&S Information Bulletin.
- M-1, Part I - Building Management Service, DM&S Manual "Operations," Change 180 - August 10, 1984.
- M-2, Part I - Clinical Affairs, DM&S Manual, Change 77 - January 14, 1986.
- Memorandum entitled "Public Affairs Posture on AIDS" - Issued to VAMC Directors - November 25, 1985.

Department of Veterans Benefits
Veterans Administration
Washington, DC 20420

DVB Circular 21-86-13

November 25, 1986

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

1. PURPOSE. This circular offers information and guidelines for the rating of diseases caused by AIDS. The information contained herein reflects the latest principles available on this relatively new issue. As additional knowledge is gained on this complex entity, amendments to this circular will be made and forwarded to field stations.

2. GENERAL. AIDS is a complex of conditions which are clinical manifestations of a defective immune system. AIDS is caused by human T-lymphotropic virus type III/lymphadenopathy associated virus (HTLV-III/LAV). It is now being recommended that the virus be called human immunodeficiency virus (HIV) and this name is now appearing in the literature. The Centers for Disease Control defines AIDS as "a case with a disease at least moderately predictive of a defect in cell-mediated immunity occurring in a person with no known cause for diminished resistance to that disease."

3. DISEASE COURSE AND PROGNOSIS

a. HTLV-III/LAV has been shown to be transmitted by intimate sexual contact, through contaminated needles or less commonly by inoculation with infectious blood or blood products. There is no evidence of airborne spread or risk of contagion through casual contact.

b. There are two types of white blood cells that are important in the diagnosis of AIDS: T-helper cells and T-suppressor cells. In normal individuals, there are large quantities of the T-helper cells which promote immunity. In AIDS victims, the T-helper cells are significantly reduced while the victims' blood contains an abnormal number of T-suppressor cells which inhibit the body's immune response system; i.e., a reversal of the normal ratio of T-helper cells to T-suppressor cells.

c. The most commonly used laboratory test in relation to AIDS is the HTLV-III/LAV antibody test. This is not a test for AIDS but detects a marker or antibody to the virus. There is a lag between infection by the virus and the development of antibodies although the duration of the lag period is unknown at present. Two antibody tests are available: the screening ELISA test and the confirmatory Western blot. A person may have a positive antibody test without any evidence of immune deficiency or AIDS. It is not known how long the virus may remain dormant before it causes disease or what

Group III. Persistent Generalized Lymphadenopathy - defined as palpable lymphadenopathy (enlargement of 1 cm. or more) at two or more extra-inguinal sites persisting for more than 3 months in the absence of a concurrent illness or condition other than HTLV-III/LAV infection to explain the findings.

Group IV. Other HTLV-III/LAV Disease - the clinical manifestations of patients may be designated by assignment to one or more subgroups. Subgroup classification is independent of the presence or absence of lymphadenopathy. Each subgroup may include patients who are minimally symptomatic as well as patients who are severely ill.

Subgroup A

Constitutional disease - defined as one or more of the following: fever persisting more than 1 month, involuntary weight loss greater than 10 percent of normal, or diarrhea persisting more than 1 month, and the absence of a concurrent illness or condition other than HTLV-III/LAV infection to explain the findings.

Subgroup B

Neurologic disease - defined as one or more of the following: dementia, myelopathy, or peripheral neuropathy, and the absence of a concurrent illness or condition other than HTLV-III/LAV infection to explain the findings.

Subgroup C

Secondary infectious diseases include *pneumocystis carinii* pneumonia, chronic cryptosporidiosis, toxoplasmosis, extraintestinal strongyloidiasis, isosporiasis, candidiasis (esophageal, bronchial, or pulmonary), cryptococcosis, histoplasmosis, mycobacterial infection with *Mycobacterium avium complex* or *M. kansasii*, cytomegalovirus infection, chronic mucocutaneous or disseminated herpes simplex virus infection, progressive multifocal leukoencephalopathy, oral hairy leukoplakia, multidermatomal herpes zoster, recurrent *Salmonella* bacteremia, nocardiosis, tuberculosis, or oral candidiasis (thrush).

Subgroup D

Secondary cancers include Kaposi's sarcoma, non-Hodgkin's lymphoma (small, noncleaved lymphoma or immunoblastic sarcoma), or primary lymphoma of the brain.

Subgroup E

Other conditions in HTLV-III/LAV infection - defined as the presence of other clinical findings or diseases, not classifiable above, that may be attributed to HTLV-III/LAV service connected as directly incurred. If the evidence of record establishes that HTLV-III/LAV infection preexisted service, the manifestation of any underlying disease in service will be considered as natural progress and service connection by aggravation will not be warranted.

d. As a general rule, no future examinations will be scheduled when a diagnosis of AIDS is established. In cases where the diagnosis is ARC, a future examination control will be established pursuant to the guidelines in 38 CFR 3.327.

e. The data on each rating decision in which AIDS is an issue will be entered into the SIRS (Special Issue Rating System).

R. J. VOGEL
Chief Benefits Director

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Veterans Administration
Department of Medicine and Surgery
Washington, D.C. 20420

CIRCULAR 10-87-64

July 8, 1987

TO : Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Follow-up on VA Patients Who Have Received Blood Products from Donors Who Have Tested Positive For Antibody to *HTLV-III/LAV

1. PURPOSE: This DM&S Circular is a revision of and rescinds DM&S Circular 10-86-119 dated October 21, 1986. The purpose of this DM&S Circular is to provide new instructions on the follow-up of VA patients who have received blood products from donors who have tested positive for antibody to Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus.

2. POLICY: VA patients transfused since March 1985 who received blood products from donors who have tested positive for antibody to Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus will receive follow-up.

3. BACKGROUND:

a. The American Red Cross and other blood procurement organizations are now supplying to each VA medical center a list of donor numbers of blood products obtained from donors that have subsequently tested positive for antibody to HIV since March 1985. The only information sent to the VAMCs from the supplying blood bank facilities will be donor number, not names of donors.

b. On June 16, 1986, the AABB (American Association of Blood Banks) published a joint statement signed by the AABB, the American Red Cross and the Council of Community Blood Centers regarding the "look-back" program, including guidelines explaining how the program may be carried out. Review of this statement will provide helpful information on the subject.

4. ACTION:

a. It is the responsibility of the medical center director or designee to determine the names of patients who received each of the units of blood or components from donors found to be positive for antibody to HIV.

*HTLV-III is now HIV (Human Immunodeficiency Virus).

THIS CIRCULAR EXPIRES ON JULY 7, 1988

b. A pre and post test counseling program will be established at each VA facility testing this group of former VA patients. The counseling program is mandatory and the information provided the patient during counseling is equal in importance to the testing. Appropriate clinical staff members should be selected for this assignment.

c. Counseling should interpret for the patient the implications of the test results. Suggested factors to be considered in counseling are those recommended in the MMWR report of March 20, 1987. The American Association of Blood Banks, American Red Cross and Council of Community Blood Centers have issued a joint statement on March 17, 1987, supporting the CDC recommendation.

d. The procurement of tests for antibody to HIV is the responsibility of the VA facility which will absorb the cost of testing. The local VA Medical center laboratory or a VA reference laboratory may be selected for testing. In some locations the American Red Cross blood bank may offer testing.

e. A positive test has the following significance as currently understood. Such persons are infected with HIV for life. And, whether symptom-free or ill, they must be considered to be potentially infectious to others by sexual transmission, by sharing of drug injection equipment or by donation of blood, semen or organs. Antibody positivity is not synonymous with having AIDS. It is not possible at present to determine which persons with antibody positivity will be ill in the future.

f. For patient oriented questions, call Dr. Howard D. Cohn (11A) (FTS 373-3560) and Dr. Susan Mather (111) (FTS 373-2549); for questions on testing, call Dr. Grace H. Guin (113) (FTS 373-2679).

4. REFERENCES: Morbidity and Mortality Weekly Report, Volume 36, No. 10, dated March 20, 1987.

5. RESCISSIONS: This DM&S Circular will be rescinded on July 7, 1985.

6. FOLLOW-UP RESPONSIBILITY: Deputy Assistant Chief Medical Director for Clinical Affairs (11B/113)

John A. Gronvall, M.D.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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j. Antibody positivity is not synonymous with having AIDS. We cannot currently predict which persons who are antibody positive will become ill in the future.

k. Patients with signs or symptoms of AIDS (Acquired Immunodeficiency Syndrome) or ARC (AIDS Related Complex) considered to have been acquired as a result of having been transfused with blood or blood components from a donor who tested positive for antibodies to HIV, will be admitted for study and care, employing tertiary testing as indicated (i.e. for example, by flow cytometry).

l. It is the responsibility of the individual medical center to comply fully with requests from blood collection agencies in the "look-back" program, but only to the extent authorized by the Privacy Act of 1974 and 38 U.S.C. 3301. These statutes permit the VA to make nonconsensual disclosure to blood collection agencies of the results of testing for the HIV antibody in the recipients of donated blood, provided the format in which such information is disclosed prevents such blood recipients from being identified by name or address. Generally, VA may not make nonconsensual disclosure of such HIV test results to any other persons or organizations. The recipients of donated blood may, of course, consent to the disclosure of their names and addresses with the results of such testing to any non-VA person or organization. Questions on authority to disclose information on HIV testing during the "look-back" program should be referred to Chief, Medical Administration Service or VA District Counsel at the local facility.

m. For patient oriented questions, call Dr. Howard D. Cohn (11A) FTS 373-3560) and Dr. Susan Mather (111) (FTS 373-2549); for questions on testing, call Dr. Grace H. Guin (113) (FTS 373-2679).

5. REFERENCES: Anderson, K.C. et al. Transfusion Acquired Human Immunodeficiency Virus Infection Among Immunocompromised Persons. Ann. Intern. Med. 1986; 105:519-527.

6. RESCISSION: DM&S Circular 10-86-119, October 21, 1986.

7. FOLLOW-UP RESPONSIBILITY: Deputy Assistant Chief Medical Director for Clinical Affairs (11B/113).

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Veterans Administration
Department of Medicine and Surgery
Washington, DC 20420

Circular 10-87-65

July 8, 1987

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics and Regional Offices with Outpatient Clinics

SUBJ: Testing Transfusion Recipients for HIV (Human Immunodeficiency Virus) Antibodies.

1. PURPOSE: The purpose of this DM&S Circular is to implement VA policy on patients transfused between 1978 and spring of 1985.

2. POLICY: If a veteran who received a transfusion at a VAMC between 1978 and the spring of 1985 comes in voluntarily requesting a test for antibody to HIV, VA physicians will provide the test. VA will obtain and document informed consent from the patient prior to testing. If the HIV antibody test is positive, discussion should include means of protecting the patient's spouse and family members. Confidentiality of the test results will be strictly maintained and the test results disclosed only as authorized by the Privacy Act of 1974 and 38 U.S.C. 3301.

3. BACKGROUND:

a. The March 20, 1987 issue of the CDC (Centers for Disease Control) MMWR (Morbidity and Mortality Weekly Report), Volume 36, No. 10, contains a report on the likelihood of HIV infection among individuals who received transfusions between 1978 and the spring of 1985. The issue of proactive notification of all transfusion recipients between 1978 and the spring of 1985 has not been addressed by CDC.

b. Many thousands of blood transfusions were administered to VA patients during this extended period from 1978 to April 1985. Response to the CDC report is likely to result in a groundswell of requests for laboratory testing services.

4. ACTION:

a. The patient will be tested by the ELISA method (enzyme-linked immunosorbent assay). If negative twice, do not repeat. If positive ~~either time~~, follow with the Western blot test for corroboration of antibodies to HIV. All patients will be informed of the results of their tests and a note will be placed in the patient's medical record on the test results.

THIS CIRCULAR EXPIRES ON JULY 7, 1988

b. A pre and post test counseling program will be established at each VA facility testing this group of former VA patients. The counseling program is mandatory and the information provided the patient during counseling is equal in importance to the testing. Appropriate clinical staff members should be selected for this assignment.

c. Counseling should interpret for the patient the implications of the test results. Suggested factors to be considered in counseling are those recommended in the MMWR report of March 20, 1987. The American Association of Blood Banks, American Red Cross and Council of Community Blood Centers have issued a joint statement on March 17, 1987, supporting the CDC recommendation.

d. The procurement of tests for antibody to HIV is the responsibility of the VA facility which will absorb the cost of testing. The local VA Medical center laboratory or a VA reference laboratory may be selected for testing. In some locations the American Red Cross blood bank may offer testing.

e. A positive test has the following significance as currently understood. Such persons are infected with HIV for life. And, whether symptom-free or ill, they must be considered to be potentially infectious to others by sexual transmission, by sharing of drug injection equipment or by donation of blood, semen or organs. Antibody positivity is not synonymous with having AIDS. It is not possible at present to determine which persons with antibody positivity will be ill in the future.

f. For patient oriented questions, call Dr. Howard D. Cohn (11A) (FTS 373-3560) and Dr. Susan Mather (111) (FTS 373-2549); for questions on testing, call Dr. Grace H. Guin (113) (FTS 373-2679).

4. REFERENCES: Morbidity and Mortality Weekly Report, Volume 36, No. 10, dated March 20, 1987.

5. RESCISSIONS: This DM&S Circular will be rescinded on July 7, 1985.

6. FOLLOW-UP RESPONSIBILITY: Deputy Assistant Chief Medical Director for Clinical Affairs (11B/113)

John A Gronvall, M.D.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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Veterans Administration
Department of Medicine and Surgery
Washington, D.C. 20420

Circular 10-87-79

August 3, 1987

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Prevention of Transmission of Infection with Human Immunodeficiency Virus (HIV) in the Work Place

1. PURPOSE: This DM&S Circular is a revision of DM&S Circular 10-86-7, dated January 24, 1986. It will not be incorporated into a manual at this time because changes in the recommendations for prevention of transmission are anticipated as the knowledge of AIDS and HIV infection increases.

2. POLICY: The VA has an infection control program at each facility to safeguard patients and employees against infections which are acquired in the facility or brought into the facility from the community. The Centers for Disease Control regularly publish guidance and recommendations concerning infection control which are covered in the medical literature and Morbidity and Mortality Weekly Report (MMWR). All local infection control policies must address AIDS and HIV infection.

3. ACTION: The recent publication in MMWR of HIV infections in three health care workers with non-needle-stick exposures to blood of infected patients reemphasizes the need for health care workers to adhere rigorously to existing infection control recommendations for minimizing the risk of exposure to blood and body fluids of all patients. As stated in the MMWR report, it is unlikely that routine serologic testing for HIV in all hospitalized patients would have had any affect on the exposures reported. It is essential that facilities make the appropriate protective supplies readily available to all employees when there is a possibility of exposure to HIV.

a. As previously recommended, routine precautions must be followed when there is a possibility of exposure to blood or other body fluids. The anticipated exposure may require gloves alone (e.g., when placing an intravascular catheter or handling items soiled with blood or equipment contaminated with blood or other body fluids). Procedures involving more extensive contact with blood or potentially infective body fluids (e.g. some dental or endoscopic procedures or postmortem examinations) may require gloves, gowns, masks, and eye coverings. Hands and other contaminated skin surfaces should be washed thoroughly and immediately if accidentally contaminated with blood. These precautions deserve particular emphasis in emergency care settings in which the risk of blood exposure is increased and the infectious status of the patient is usually unknown.

b. Previous recommendations have emphasized management of parenteral and mucous membrane exposures of health-care workers. In addition, health-care workers who are involved in incidents that result in cutaneous exposures involving large amounts of blood or prolonged contact with blood - especially when the exposed skin is chapped, abraded, or afflicted with dermatitis - should follow these same recommendations.

THIS CIRCULAR EXPIRES ON AUGUST 2, 1988

c. Serologic testing and appropriate counseling should be available to all health-care workers who are concerned that they may have been infected with HIV.

d. Questions may be referred to the Program Chief, Pulmonary and Infectious Diseases, VA Central Office, Medical Service (111), FTS 375-2450.

4. REFERENCES:

a. CDC Update: Human Immunodeficiency Virus Infections in Health Care Workers Exposed to Blood of Infected Patients. MMWR 1987; 36:2285-289.

b. CDC Summary: Recommendations for preventing transmission of infection with human T-lymphotropic virus type 111/lymphadenopathy associated virus in the workplace. MMWR 1985; 34:P 681-5, 691-5.

c. CDC Recommendations for preventing transmission of infection with human T-lymphotropic virus type 111/lymphadenopathy-associated virus during invasive procedures. MMWR 1986; 35:221-3.

d. CDC Recommended infection-control practices for dentistry. MMWR 1986; 35:237-42.

5. RESCISSIONS: DM&S Circular 10-86-7. This DM&S circular will be rescinded on August 2, 1988.

6. FOLLOW-UP RESPONSIBILITY: Assistant Chief Medical Director for Clinical Affairs (111).

John A. Gronvall, M.D.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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Department of Medicine and Surgery
Washington D C 20420

Veterans Administration

IL 10-87-24

October 15, 1987

CHIEF MEDICAL DIRECTOR'S LETTER

In Reply Refer To 10A7

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Informed Consent and Testing for HIV (Human Immunodeficiency Virus) Antibodies

1. PURPOSE: In view of the increased use of HIV (formerly known as HTLV III) antibody tests both inside and outside the VA, this letter summarizes the recommendations for informed consent in relation to HIV testing.

2. BACKGROUND: The HIV antibody test which was approved by the FDA for screening donated blood uses the ELISA (enzyme-linked immunosorbent assay) technology. It is being widely used as a screening test for persons at risk of HIV infection in combination with the confirmatory Western Blot test. VA medical centers are reporting increased interest in HIV testing on the part of patients and staff. Testing in the VA is voluntary and includes counseling before the test is performed and when the results are given to the patient. Many VA medical centers have decided that written informed consent should be obtained and a variety of consent forms have been developed to document consent and provide some of the elements involved in counseling patients about the test.

3. DISCUSSION: It is VA policy that every patient receiving treatment at a VA facility has the right to informed participation in decisions involving his or her health care. Chapter 23 of M-2, Part I, dated August 27, 1982, outlines the requirements of the VA's informed consent policy set out in VA regulations at 38 C.F.R. Section 17.34. Such regulations are required by law. The chapter pre-dated the advent of HIV testing. However, the General Counsel has given the opinion that written informed consent for the blood test for HIV antibody is not legally required because "informed consent" is not necessarily a written permission for treatment from the patient, but rather an exchange of information between the health care practitioner and the patient which results in the patient's (or their representative) freely consenting to a medical procedure or treatment while being aware of the consequences. A written consent form, even if signed by the patient will not constitute legally sufficient informed consent unless preceded by the requisite exchange of information. Indeed, suits have been brought by patients who alleged that their informed consent was not obtained despite signed consent forms. Reliance on a form carries a risk that the health care provider will:

a. Rely on the form instead of providing information to the patient that the patient can understand about the consequences of the HIV test, and

b. Fail to record that the exchange of information took place in the patient's record.

4. RECOMMENDATIONS:

a. HIV testing in the VA is voluntary and based on clinical indications such as known or suspected exposure or clinical symptoms.

b. Counseling is an integral part of any testing program and should occur prior to the test and at the time the results are given.

c. The patient should be aware that their medical record will contain the test results. The VA is not an anonymous test site but many communities do have services or test sites where patients can be referred.

d. Consent forms are neither required nor recommended. However, if used as a local option they are legal documents and should be reviewed for their lucidity, medical content and legal implications.

5. REFERENCES:

a. M-2, Part 1, Chapter 23. Informed Consent, August 27, 1982.

b. IL 11-85-12 - Clinical Affairs Letter - HTLV-III Testing in VA Facilities, December 31, 1985.

c. Circular 10-86-119 - Follow-up on VA Patients who have Received Blood Products from Donors who have Tested Positive for Antibody to HTLV-III. October 31, 1986.

6. Questions may be referred to the Chairman, AIDS Working Group (10A7), FTS 373-2621 or 373-3631.

John A. Gronvall, M.D.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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Veterans Administration
Department of Medicine and Surgery
Washington, DC 20420

CIRCULAR 10-87-140

December 4, 1987

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities; Domiciliary; Outpatient Clinics; and Regional Offices with Outpatient Clinics

SUBJ: Case Reporting of Acquired Immune Deficiency Syndrome (AIDS) According to the New CDC Surveillance Definition (RCS 10-0116)

1. PURPOSE: This DM&S Circular is a revision of the DM&S Circular 10-86-96 and contains significant changes. It will not be incorporated into a manual because changes are anticipated as other information and data collection systems are developed to meet the Agency's needs.

2. POLICY: Case reporting of AIDS was begun in the VA in August of 1983 using the first CDC surveillance definition of AIDS published in Morbidity and Mortality Weekly Report (MMWR) in 1982. Reporting has continued since that time using the 1985 revised case definition incorporating evidence of the underlying infection with the Human Immunodeficiency Virus or HIV (formerly called HTLV-III). In August 1987, another revision of the surveillance case definition was published which will now be used in reporting of VA AIDS cases to the Centers for Disease Control (CDC) via local health departments and to VA Central Office. Only newly diagnosed cases need to be reported to CDC. However, all cases which are new to the VA facility regardless of whether they have been reported by other VA or non-VA facilities should be reported to VACO.

The presumptive diagnoses described in Appendix III of the MMWR Supplement 1S describing the revised case definition has been questioned by the VA Steering Committee on AIDS and are under review. It is assumed that in the VA, the high level of diagnostic capability and laboratory support will lead to few reported cases on a presumptive basis. However when this does occur, the case should be clearly marked as presumptive diagnosis when reported.

3. ACTION: A report is required for each AIDS patient that is new to the reporting facility. To standardize this reporting, a copy of the CDC form (CDC 50.42 REV 8-87) is preferred. It is important that this form contain the name of the patient or a locally determined tracking code in order that duplicate reporting be avoided. Facilities will complete the CDC form retaining one copy at the facility and forward one copy to the Chairman, AIDS Working Group (10BA__/10A7) within 30 working days. Questions can be referred to Dr. Robert Allen, AIDS Working Group, FTS 373-2621/3631/3072.

4. REFERENCES:

a. M-2, Chapter 24, Part 1, Change 68 (January 13, 1983), Medical Alert System.

b. CDC:MMWR 36: No. 1S, August 14, 1987. Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome.

THIS CIRCULAR EXPIRES DECEMBER 2, 1988

5. RECISSIONS: None. DM&S Circular 10-86-96 expired August 14, 1987. This DM&S Circular will be rescinded on December 4, 1988.
6. FOLLOW-UP RESPONSIBILITY: Chairman, AIDS Working Group (10A7) FTS 373-2621, -3631, -3072.

ARTHUR J. LEWIS, M.D.
Deputy Chief Medical Director

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Department of Medicine
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Veterans
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IL 10-88-2

CHIEF MEDICAL DIRECTOR'S LETTER

In Reply Refer To
10B/AIDS

January 28, 1988

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliaries, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: HIV (Human Immunodeficiency Virus) Testing Experience in VA Health Care Facilities: National Survey Results

1. PURPOSE: This letter summarizes the results of the Survey of HIV Testing in VA Health Care Facilities conducted in September 1987 in accordance with Circular 10-87-100, (RCS 10-87-8).

2. BACKGROUND: The tests for antibodies to HIV, the retrovirus which causes AIDS (Acquired Immunodeficiency Syndrome) are being widely used to screen the blood supply, confirm the diagnosis of diseases related to HIV infection, and to screen persons at high risk of infection so that they can receive counseling designed to reduce transmission of the virus. The Department of Medicine and Surgery is developing a model program of HIV Testing and Education. The first step in this development was a baseline survey of the practices and experience as of September 1987. At that time 2,861 patients with AIDS had been reported by 116 VA medical centers, representing approximately 6% of all the AIDS patients in the United States. However, almost half (49%) of the VA AIDS patients were seen in eight medical centers in the epicenters of the disease.

3. DISCUSSION: The survey questionnaire was sent to 167 facilities and all returned it. Only 10 facilities reported that they had not yet treated any patients with AIDS or ARC (Aids Related Complex). Ninety-four facilities (56.3%) had a written policy for HIV testing but all reported that physicians could order the test for patients. The majority of medical centers (51%) used either their own or the VA Serology Reference Laboratory for ELISAs. The others used either DOD (Department of Defense), commercial, affiliated hospital, blood bank, or health department laboratories. Sixty-two percent used VA laboratories for the Western blot. For those using outside laboratories, the charges ranged from $1.75 to $110 (average $16.62) for the ELISA and $1.75 to $177.50 (average $44.46) for Western blots. The VA Reference Lab estimates that their actual costs are $3.00 and $15.00 respectively.

The numbers of tests done have risen steadily over the past 3 years:

YEAR	ELISA	WESTERN BLOT
1985	4,708	570
1986	13,691	1,760
1987	33,185	3,335

Ninety-nine percent of all VA medical centers made the test available to patients with signs and symptoms of disease and most (92-94%) made the test available to patients with a history of blood transfusions or intravenous drug abuse. Only 54% of all facilities offered the test to pre-operative patients.

One hundred and five facilities estimated the average amount of time spent in pre-test counseling and the overall average was 18 minutes. The patient's primary care physician was responsible for the counseling in over 50% of the time. In an additional 34 facilities (20.9%) the responsiblity was shared between a nurse and the physician. The Infectious Diseases Section did the counseling at 17 (10.4%) VA medical centers and only nine (5.5%) had a multidisciplinary team involved.

One disturbing finding of the survey was that 33 facilities (19.8%) reported that they did not obtain informed consent from all patients prior to testing. Following the survey, a Chief Medical Director's Letter (IL 10-87-24) was published stressing the importance of informed consent. In the VA, HIV testing is voluntary and is performed only after counseling the patient and obtaining their consent.

4. RECOMMENDATIONS:

a. In view of the increased interest in and emphasis on HIV testing in both the health care community at large and the Veterans Administration, it is recommended that VA medical centers develop local plans and policies for testing. These plans must reflect the Agency policy on testing:

(1) Testing is voluntary and requires informed consent.

(2) The results of the HIV tests are confidential and are kept in the patient's medical record.

(3) A positive HIV test in the VA consists of two positive ELISAs and a confirmatory positive Western blot.

(4) Counseling is an essential part of any testing program in the VA. Pre-test counseling is aimed at educating the patient to make an informed valid decision about whether to undergo testing. Post-test counseling must both educate the patient about halting the transmission of the virus and what to expect in the future and also provide any necessary medical and psychosocial support.

b. The variability of costs for both the ELISA and Western blot tests makes it essential that VA medical centers plan for the most cost-effective testing procedures consistent with rigorous quality assurance standards.

5. REFERENCES:

a. Circular 10-87-100 - Survey of Testing in VA Health Care Facilities - (RCS 10-87-8), August 31, 1987.

b. IL 10-87-24 - Chief Medical Director's Letter - Informed Consent and Testing for HIV (Human Immunodeficiency Virus) Antibodies, October 15, 1987.

6. Questions may be referred to the Director, AIDS Program Office (10B/AIDS), FTS 373-2621 or 373-3631.

John A. Gronvall, M.D.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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CIRCULAR 10-87-79
SUPPLEMENT No. 1

Veterans Administration
Department of Medicine and Surgery
Washington, DC 20420

February 4, 1988

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Prevention of Transmission of Infection with HIV (Human Immunodeficiency Virus) and Other Bloodborne Agents in the Workplace (by the use of Universal Precautions)

1. PURPOSE: This supplements and expands DM&S Circular 10-87-79, dated August 3, 1987, in accordance with new requirements published by the Department of Labor, OSHA (Occupational Safety and Health Administration), and the Department of Health and Human Services CDC (Centers for Disease Control) relating to the practice of infection control in VA health care facilities. It will not be incorporated into a manual because this is the first of several communications on the subject which are anticipated.

2. BACKGROUND: The VA has an infection control program at each health care facility to safeguard patients and employees against infections which are acquired in the facility or brought into the facility from the community. VA facilities have followed the recommendations of the CDC in formulating infection control policy and all local policies addressing AIDS and HIV infection. Since 1986, CDC has recommended that routine barrier protection be used when there was the possibility of exposure to blood or body fluids. On October 30, 1987, the Secretaries of Labor and Health and Human Services published a Joint Advisory Notice concerning Occupational Exposure to HBV (Hepatitis B Virus) and HIV. The notice explains to employers how to implement the protective guidelines and spells out that employers can be held accountable for failure to implement the guidelines which were previously considered voluntary.

3. POLICY: DM&S facilities will follow the recommendations of CDC relating to the prevention of transmission of HIV and HBV in the health care setting and comply with the rules promulgated by OSHA on the subject.

4. ACTION: Facilities must begin the formal process of implementing what has been termed "Universal Precautions" for the protection of employees who are exposed to blood, body fluids, and tissues which can transmit disease according to the guidance provided in the Joint Advisory Notice. This will involve a multidisciplinary effort that must include both Medical Center Infection Control and Safety Committees. DM&S Regional Safety technical support staff is available to provide assistance. The following steps will be necessary but are not intended to be an exhaustive summary of the process:

a. Evaluate all working conditions and identify tasks that employees are expected to encounter as a result of employment. The tasks will then be categorized by risk of exposure and protective measures required.

b. Educate staff and patients about the need for such protective measures. Establish and document initial and periodic training programs for all employees at risk of exposure on standard operating procedures, work practices, and protective equipment.

c. Institute engineering controls where appropriate. (e.g. the ready availability of puncture resistant containers for the disposal of sharps and needles will reduce the hazards of cuts and needlestick injuries.)

d. Establish voluntary monitoring (i.e., at the request of the employee) for HBV and HIV antibodies following known or suspected exposures; and, medical counseling must be offered without cost to the employee. Voluntary HBV immunization is also included in the Joint Advisory Notice.

5. REFERENCES:

a. CDC Recommendations for Prevention of HIV Transmission in Health-Care Settings. MMWR Supplement: 32:2S, August 21, 1987.

b. Department of Labor, Office of the Secretary, Joint Advisory Notice: Department of Labor/Department of Health and Human Services: HBV/HIV: Notice. Federal Register: 52:210:41818-24, October, 30, 1987.

6. RESCISSIONS: This DM&S Circular will be rescinded February 3, 1989.

7. FOLLOW-UP RESPONSIBILITY: Director, AIDS Program Office (10B/AIDS), FTS 373-2621 or 373-3631.

John A. Gronvall, MD.
JOHN A. GRONVALL, M.D.
Chief Medical Director

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Department of Medicine and Surgery
Washington D C 20420

Veterans Administration

IL 14-88-1

March 29, 1988

In Reply Refer To 142E

ACADEMIC AFFAIRS LETTER

TO: Regional Directors; Medical District Directors; Directors, VA Medical Center Activities, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics

SUBJ: Announcement of the VA's National Education Plan on AIDS (Acquired Immunodeficiency Syndrome) and HIV (Human Immunodeficiency Virus) Infection, FY 88-90

1. This letter describes the major components of an education plan on AIDS and HIV Infection initiated by the Office of Academic Affairs in FY 88 to provide a more unified, coordinated approach to AIDS/HIV educational activities already occurring at VA medical centers.

2. All VA medical centers will, in time, care for veterans with HIV infection and AIDS related conditions. While research efforts are underway all over the country and the world, the single most important element in the battle against HIV infection and AIDS is education to promote behaviors that prevent transmission and reduce the risk of HIV infection, as well as education to dispel fears and misinformation. Failure to provide the needed education in the health care setting may result in problems with employee morale, the inappropriate refusal to provide health care or come into contact with patients, and limit the health worker's abilities to teach, counsel, and/or provide accurate information to the patient, family, and public.

3. A needs assessment survey in FY 87 by VA Central Office identified AIDS as the number one VA national training priority. Recognizing the need for effective, broad-based education about AIDS and HIV infection to supplement already existing educational efforts at many VA medical centers, the Office of Academic Affairs established an AIDS Education Task Force and linked its efforts to the Steering Committee on AIDS and the Program Office on AIDS, VA Central Office. The Task Force, with an Advisory and Working Group, formulated a system-wide AIDS/HIV Infection Education Plan for FY 88-90. The following elements of the national training programs are now underway:

"America is #1—Thanks to our Veterans"

a. INTRODUCTORY ACTIVITIES:

Two Health Satellite Network Programs directly reaching fifty VA facilities have been produced. The first program "Infection Control Response to AIDS: Universal Precautions" was broadcast on 1/19/88. The second program titled "The HIV Challenge: The VA Response" was broadcast 2/16/88, and included presentations on the impact of the AIDS epidemic, VA policy and planning directions in patient care, a report of VA research activities, and the VA's national AIDS and HIV infection education plan. Videotapes of both programs should be at all medical centers. If your facility has not received a copy by 4/1/88, contact Paul Smith, Regional Learning Resources Services, VAMC Salt Lake City, FTS 588-1208. You are strongly urged to make the availability of these programs known within your medical center. Library Service will distribute the tapes, as needed, for showing to your staff.

b. INTENSIVE, ON-GOING ACTIVITIES:

(1) An AIDS/HIV Infection Education Train-The-Trainer Program is designed to supplement the HIV infection education activities already available at many VA medical centers. Implemented by the RMECs (Regional Medical Education Centers), the first program will begin May 1988 at the Northeast RMEC. By the end of FY 88 two or more individuals in each VA medical center will be trained and capable of conducting AIDS and HIV infection training sessions for VA personnel. Program announcements including selection criteria for applicants will be issued by the RMECs.

(2) A Patient Health Education: Prevention of HIV Infection/AIDS Program will prepare direct care givers to conduct pre- and post-HIV antibody test counseling and encourage HIV prevention, particularly with populations with high-risk behaviors. The program will be pilot tested in the fourth quarter of 1988 and implemented by the RMECs in FY 89. It is intended to have two or more staff trained at each VA medical center by the end of FY 89.

(3) Development and Dissemination of AIDS and HIV Infection Education Materials as well as updating and maintaining this information is part of the VA's AIDS/HIV Infection education plan. The Centers for Disease Control's current brochure "What You Should Know About AIDS" is being revised and a new brochure will be available June 1988. As with the Surgeon General's Report on AIDS, this brochure should be useful for the education of veterans, their beneficiaries, and VA employees. Reflecting the theme "America Responds to AIDS," the brochure will convey facts about AIDS, how it is and is not transmitted, ways to prevent infection, and what the reader should tell others. The brochure will be available from the government free of

charge. VAMCs may request copies of the revised brochure by writing the National AIDS Information Clearinghouse, PO Box 6003, Rockville, Maryland, 20850. VAMCs are encouraged to also continue using the Surgeon General's Report on AIDS (distributed to VA medical facilities in January 1987) by requesting additional copies from the Publications and Control Officer at their facility, referencing IL 10-86-23. When the VA depot supply is exhausted, copies can then be obtained without charge by writing the National AIDS Information Clearinghouse.

4. A positive development in the AIDS epidemic is the increasing cooperation among clinicians, educators, and administrators at all levels. The local, regional, and national levels are working together to support AIDS and HIV infection education at the 172 VA medical centers across the nation. Obviously education is not a cure for AIDS and HIV infection, but it does have the greatest potential for limiting not only the spread of the disease, but the fear that accompanies it. With the comprehensive programs planned coupled with those already in operation, we are of the opinion that the VA can be used as a model of care for the nation. Your on-going cooperation and support of these efforts are essential.

Peter F Regan MD

PETER F. REGAN, M.D.
ACMD for Academic Affairs

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TEST RESULTS FOR AIDS

I have been advised that test results that are positive for AIDS are getting onto the computer system. A policy is now being written by the AIDS Program Office and Pathology Service (Veterans Administration Central Office) that will state that AIDS test results from patients (or employees) may not be placed on the computer system. It is imperative that the result gets onto the chart and we must not enter AIDS results on the computer. This is a violation of the Privacy Act. Contact Person: Susan Mather, M.D., AIDS Program Office (10B/AIDS), FTS: 373-3072.

SOURCE: TWX, IL 10B-88-5, April 4, 1988, page 6 of 16.

EMPOWERMENT SCRIPT

"YOU have COURAGE"

**"YOU are
COMPASSIONATE"**

**"YOU have made a
COMMITMENT"**

"YOU are CONNECTED"

"THANK YOU for CARING"

I Love Myself The Way I Am

I love myself the way I am
there's nothing I need to change
I'll always be the perfect me
there is nothing to rearrange.
I am beautiful and capable of
being the best me I can.
And I love myself just the way I am.

I love you just the way you are.
there is nothing you need to do.
When I feel the love inside myself
it's easy to love you.
Behind your fears, your rage and tears
I see your shinning star
And I love you just the way you are.

I love the world the way it is
as I can clearly see
That all the things I judge are done
by people just like me.
So' til the birth of peace on earth
that only love can bring.
I'll help it grow by loving everything.

I love myself the way I am
but still I want to grow
The change outside can only come
when deep inside I know
I am beautiful and capable of being the best me I can,
and I love myself just the way I am
I love myself just the way I am.

From: LOVING YOURSELF
Songs & Meditations
Louise L. Hay and Jai Josefs

☆ GPO: 1990—776-056